

UNIVERSITY OF CAPE TOWN

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**An Exploration into Nephrology Nurses' Lived Experiences
of Caring for Dying Patients with End Stage Kidney Disease
following Withdrawal of Dialysis.**

Submitted to the University of Cape Town in Fulfilment of
the Requirements for the Degree
Master of Science (Nursing)

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Supervisor: Dr NA Fouché

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An Exploration into Nephrology Nurses' Lived Experiences of Caring for Dying Patients with End Stage Kidney Disease following Withdrawal of Dialysis.

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Abstract

The aim of this study sets out to better understand nephrology nurses' lived experiences of dying and deaths of patients with ESKD following withdrawal of dialysis.

A qualitative research design using an interpretative phenomenological approach was used to explore the experiences of a purposive heterogeneous sample of eight nephrology nurses who were working in private dialysis units. Information was gathered by phenomenological conversations and feed-back sessions. Colaizzi's phenomenological method was employed to formulate four main themes:

1. Emotional trauma
2. Detachment
3. Loss of altruistic values in nursing
4. *being-with-death*

For the participants in this study, emotional trauma was the most significant. The participants experienced a sense of powerlessness which caused emotions of hopelessness and anger and subsequently a sense of premature mourning and detachment. This state of hopelessness proved to be an obstacle in patient care, resulting in the altruistic values of nursing to be no longer applied. The participants' ontological confrontation of *being-with-death* was evident, as they came to terms with the reality of their own death. Recommendations are offered to address the educational aspects of death and dying for nephrology nurses. This study endorses the need for further research into patients with ESKD 'end-of-life' which can influence how healthcare professionals should treat these patients during this phase.

Keywords: Dialysis withdrawal, Palliative/hospice care, Renal nursing/Nephrology, Death anxiety, Grief in the nursing profession.

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Definition of Terms

Arteriovenous Fistula (AVF)

The communication between artery and vein which is surgically created to provide a site for haemodialysis access (Dorland, 2012, p. 705).

Body-Mass Index (BMI)

A formula for determining obesity, which is calculated by dividing a person's weight in kilograms by the square root of the person's height in meters (Mosby, 2006, p. 237). A BMI between 18 and 25 is considered normal for men and women (Lee, 2003, p. 887), a BMI of 25 to 29.9 is viewed as overweight and BMI of 30 and more is considered as obesity (Stunkard, 2003, p. 914).

Chronic Kidney Disease (CKD)

The abnormalities in kidney structure which impairs the function of the kidney for a duration of three months or more (Andrassy, 2013, p. 5).

Comorbid Disease

A condition pertaining to a disease or other pathologic condition that occurs simultaneously with another. Such conditions include hypertension, diabetes and chronic glomerular nephritis (Dorland, 2012, p. 392).

Dialysis or Renal Replacement Therapy

A treatment modality to remove the waste products and excess fluids from the body. There are two modalities of dialysis: haemodialysis (HD) and peritoneal dialysis (PD) (Cutler, 2003, p. 833).

Haemodialysis Catheter

A surgical catheter inserted in the vein of the neck, chest and/or leg and used on a temporary basis for vascular access for haemodialysis (Dorland, 2012, p. 309).

End-of-Life Care (EoLC)/Palliative Care

Measures taken to keep a terminally ill person as comfortable as possible (Dubler, 2003, p. 56).

End Stage Kidney Disease (ESKD)

When the Glomerular Filtration Rate (GFR) is ≤ 15 ml/min the resulting ESKD occurs usually culminating in the death of the patient (Andrassy, 2013). Based on Kidney Disease Improved Global Outcome (KDIGO) (2013) guidelines, CKD is classified into five stages according to GFR (Table 1) (Andrassy, 2013). In stages one to four, the focus is to treat the cause and associated comorbid conditions in order to prevent further kidney damage. The most advanced and severe stage is five and is often referred to as ESKD. The dialysis or transplantation is often required in order for the patient to survive (Ho, Barbero, Hidalgo, & Camps, 2010).

Table 1. Classification of CKD based on GFR (Andrassy, 2013, p. 5).

GFR category (Stages)	GFR (mL/min/1.73m ²)	INTERPRETATION
1	>90	Normal or high
2	60-89	Mildly decreased
3a	45-59	Mildly to moderate decreased
3b	30-44	Moderate to severely decreased
4	15-29	Severely decreased
5	0-15	Kidney failure

Glomerular Filtration Rate (GFR)

The volume of plasma filtered from the glomerular capillaries into Bowman's capsule each minute and expressed in mL/min. The average GFR for a young adult is between 100-125mL/min ((Schira, 2015, p. 13).

Haemodialysis (HD)

The process in which blood is removed from the body and pumped by a machine outside of the body into a dialyser. The dialyser is often referred to as an artificial kidney, which filters

metabolic waste products from the blood and returns the purified blood into the body (Cutler, 2003, p. 834).

Nephrologist

A medical doctor/specialist in nephrology (Dorland, 2012, p. 1241).

Nephrology

The scientific study of the kidney, its anatomy, physiology, pathology and pathophysiology (Dorland, 2012, p. 1241).

Nephrology Nurse

A specialised registered nurse who is able to care for patients and their families with kidney failure (Tong, Lowe, Sainsbury, & Craig, 2008).

Peritoneal Dialysis (PD)

The peritoneum, a membrane that lines the abdomen and covers the abdominal organs, is used as a filter during the dialysis process (Cutler, 2003, p. 834).

Peritoneal Dialysis Catheter (Tenckhoff)

A catheter inserted into the peritoneal cavity to provide peritoneal dialysis. It consists of a flexible silicone rubber tube at the end with side holes and one or two extra-peritoneal dacron felt cuffs to prevent infections (Dorland, 2012, p. 309).

Post-traumatic stress disorder (PTSD)

PTSD is a mental health condition that's triggered by a terrifying event, either by experiencing it or witnessing it (Mayoclinic, 2018)

Abbreviations

ACP: Advanced Care Plan

CHD: Chronic Haemodialysis

DSM-IV: Diagnostic and Statistical Manual of Mental Disorders

EoLC: End- of- Life-Care

ESKD: End Stage Kidney Disease

GDP: The per capita gross domestic product

ICAS: Independent Counselling Advisory Services

KDIGO: Kidney Disease: Improving Global Outcome

PD: Peritoneal Dialysis

Pmp: per million population

PTSD: Post-Traumatic Stress Disorder

SANC: South African Nursing Council

SARR: South African Renal Registry

Personal interest in the research topic

My interest for this study was based on personal experience as a nephrology nurse. One such experience is about a patient named Charles (name has been changed) who died from EKSD, after dialysis withdrawal.

Charles was not just my patient, but also a friend and a teacher. Mr Charles would speak to me in French and I responded in Afrikaans. He was excited to learn French and I was excited to learn Afrikaans. He was committed to learning five words in French and I was likewise committed to learning five words in Afrikaans. These learning sessions occurred during his dialysis treatments and a bond of friendship developed. Mr. Charles was a church minister and travelled abroad and I had to arrange for his dialysis sessions before he left South Africa. Suddenly, Mr. Charles' medical-aid was depleted, and I received a call from the Dr's secretary to inform the unit that his dialysis was suspended until he sorted the matter with the medical aid fund. Even though Mr. Charles was informed, he still came to the unit, under the impression that we would continue to dialyse him. Unfortunately, he was refused treatment.

After a week, Mr. Charles came to the unit, pushed in his wheelchair by his cousin. He sent a unit security guard to come to call me. When I went out to see Mr. Charles, I could hardly recognize him as his face was puffy, his whole body was swollen, and he was struggling to breathe. Mr. Charles could hardly see, as his eyelids were covering his eyes due to the swelling. Mr. Charles said in an appealing and desperate tone, "My friend, please put me on the machine, you are the only one who can save my life". Unfortunately, in my capacity as nurse, I could not make that decision and I felt embarrassed, useless, powerless, worthless and hopeless.

I called the doctor to advocate for Mr. Charles, but the response was to transfer the patient to a provincial tertiary hospital, but at such places there is no dialysis and if there was, Mr. Charles was not going to be accepted due to his age and other comorbid diseases that afflicted him. I felt despondent and had a strong desire to quit my employment and search for work elsewhere.

Mr. Charles was turned away and his cousin took him to the provincial hospital. After three days, his cousin called the unit to tell us that he passed away. Today, I still feel guilty about his

death as I felt that I could have somehow put him on the machine. I truly miss him, and I also miss him teaching me the Afrikaans language to the extent that I no longer have an interest in learning the language again.

Chapter One

Introduction

1.1. Background to the study

Nephrology nurses form a close relationship with both the patient and the family due to the long term duration of patient care (Hayes, Bonner, & Douglas, 2015; Morehouse, Colvin, Maykut, & Frauman, 2001; Polaschek, 2003). Patients may receive dialysis for up to three times a week, and in some cases for years or decades, depending on their lifespan (Brown, Bain, Broderick, & Sully, 2013; Hayes et al., 2015; Morehouse et al., 2001). In caring for patients with ESKD, nephrology nurses are also required to care for the family members and other carers (Zyga, Malliarou, Lavdaniti, Athanasopoulou, & Sarafis, 2011). This may require them to be part of the decision-making process when considering palliative care or End of Life Care (EoLC) (Price, 2003).

Due to limited healthcare facilities and budget restrictions within government subsidised dialysis units, most patients are left with no other choice but to be treated in the private dialysis units (Moosa, 2010). Often the discontinuation of dialysis is due to the depletion of medical insurance funds or at the request of the patient and/or family who feel that the renal replacement therapy no longer offers any health benefits to the patient (Moosa, Meyers, Gottlich, & Naicker, 2016). The nephrologist may also decide in discontinuing dialysis when conditions deteriorate or when dialysis access fails (Cohen, Moss, Weisbord, & Germain, 2006). For those involved, withdrawal of dialysis means death of the patient (Moss, 2000; Russ, Shim, & Kaufman, 2007). Death may occur within eight to ten days as the toxins and the excess body fluids accumulate within the body (Moss, 2000).

For nephrology nurses, the fear and anxiety of impending death of a patient is very real (Russ et al., 2007). The literature highlights the near invisibility of impending death and the anxiety experienced by nephrology nurses who care for patients with ESKD (Ashby et al., 2005;

Murtagh, Spagnolo, Panocchia, & Gambaro, 2009; Noble, Meyer, Bridges, Kelly, & Johnson, 2008). However, there is a dearth of research exploring and understanding carers' experiences of dying and deaths of these patients after dialysis withdrawal.

In the private dialysis units, most of the patients with ESKD are elderly and others with ESKD have associated comorbidities. Considering this, these ill patients are frequently rejected by the government renal dialysis units, as they do not meet the criteria to be admitted into the dialysis program.

+1.2. Overview of dialysis withdrawal in the private dialysis units

Refusal of dialysis admission within the government healthcare institutions, causes patients with ESKD to seek for treatment in the private sector. The withdrawal of dialysis occurs not only due to medical complications but also to the depletion of medical funds. The numerous reasons for government subsidised dialysis units refusing patients with ESKD into the programme include (i) medical, (ii) demographic and (iii) socio-economic factors.

Medical conditions such as diabetes and other comorbidities were proven to reduce patient post-transplant survival (Jassal, Schaubel, & Fenton, 2005; Moosa et al., 2016; Revanur et al., 2001). Jassal et al. (2005), reported that a five-year survival rate existed for 79-85 % of diabetic patients and 86% - 90% of non-diabetic patients within the age group of 50-59 years. Obesity was found to be associated with delayed graft function due to atherosclerotic and cardiovascular diseases risk and hence short-term mortality (Kovesdy et al., 2010). Patients with other medical conditions such as Human Immunodeficiency Virus (HIV), Acquired Immune-Deficiency Syndrome (AIDS) and Hepatitis B associated with ESKD, had almost no chance to be admitted to these settings (Moosa, 2010).

In line with demographic factors, the data from the 2002 Canadian Organ Replacement Registry also demonstrated that old age was shown to be associated with a decline in survival rate after kidney transplantation. Older patients have more comorbid conditions and are at a

greater risk of developing other complications during dialysis and are also subjected to long-term hospital stay or further surgical procedures (Jassal et al., 2005). Graft survival in the context of race disparities, black patients were reported to have a poorer survival rate than non-black population (Gordon, Ladner, Caicedo, & Franklin, 2010). Gordon and colleagues suggested that this may be due to the differences in immunology or in socio-economic status. Furthermore, Rayner (2008) identified gender as another important factor and indicated that women presented with a higher mortality rate after kidney transplantation. The author proposed that this may be since women develop cytotoxic antibodies from pregnancy which may increase the possibility of rejection (Rayner, 2008).

The socio-economic factors also need to be taken into consideration for admission into government healthcare dialysis units. Patients living in sub-standard housing with no running water are declined entry onto the programme, as these conditions are associated with infection risk and graft rejection (Moss, 2000). Substance abuse, a social issue is considered to increase the risk of graft rejection (Machnicki et al., 2009). Tobacco smoking is associated with cardiovascular diseases such as diabetes and hypertension which are both hazardous for graft rejection, following transplantation (Hurst et al., 2011). Poor treatment compliance and a history of non-adherence to medication have been shown to impact graft rejection (Dobbels et al., 2009).

Taking into consideration the medical and socio-economic circumstances, decisions have to be made with regards to treatment options. Admission into the Western Cape Department of Health dialysis units are based on selection criteria. The admission selection committee is often referred to as the '*Life or Death Committee*' (Moosa & Kidd, 2006, p. 1109). Moss also described this committee as the '*God Committee*' (Moss, 2000, p. 256). These analogies arise from decisions that are made to determine who lives or who dies (Erek et al., 2004; Moosa, 2010). '*God Committees*' or '*Life and Death Committee*' comprise of a nephrologist, the patient's general practitioner (GP), a social worker and the nursing and allied staff caring for the patient. Most of the patients with ESKD admitted to the private dialysis units are those patients with a good socio-economic portfolio, especially those whose treatments will be

covered by medical aid and/or the family. It is not uncommon for the extended family to collectively make a monthly contribution so that their loved ones may live a little longer. These patients may require more attention as they are often elderly and weak with a compromised immunity. Therefore, withdrawal may occur due to the depletion of funds or to the deterioration of other medical conditions.

1.3. Problem statement

Over the last six years, I worked as a nephrology nurse in the private dialysis unit in Cape Town. Within this period, I have observed an increasing number of nephrology nurses who report being sick and absent from work and others leaving the profession after caring for dying patients with ESKD following dialysis withdrawal. Often nephrology nurses experience symptoms related to the deaths of their patients with whom they have forged a bond. This may be a reason among others such as job stress, insufficient staffing, opportunity, and work motivation, for a high attrition rate of staff resignation in this discipline (Davies et al., 1996; Peeler, 2015; Rickerson et al., 2005). Therefore, there is a need to understand the living experiences of these nurses to inform nurse managers and educators on how to better develop appropriate caring strategies. Table 2 shows the death rate of the patients with ESKD in the research settings between the year 2013 and 2017.

Table 2. Death rate of patients with ESKD in the dialysis study settings (2013-2017).

Year	Total Deaths	Natural Deaths	Deaths after Dialysis Withdrawal	Overall % of Death Occurrence after Dialysis Withdrawal
2013	26	20	6	23
2014	17	14	3	18.6
2015	36	31	5	13.9
2016	28	22	6	21.4
2017	25	21	4	16
TOTAL	132	108	24	18.2

1.4. Research question

What are the lived experiences of the nephrology nurses caring for the dying patients with ESKD, following dialysis withdrawal?

1.5. Aims and objectives

The aim of this study sets out to have a better understanding of the nephrology nurses' lived experiences of dying and of the deaths of patients with ESKD following withdrawal of dialysis. In this context, the nephrology nurses' experiences may offer an opportunity to inform, understand and attend to the educational and emotional needs that these nurses face whilst caring for patients with terminal renal disease. To achieve this aim, the following three objectives are set out:

1.6. Pre-understandings

Often a novice researcher has pre-understandings of the phenomenon (a) under study, which may guide the research methodology in the research process (Cresswell, 2007). A qualitative research design, describes 'the perceived view of reality' suggesting that 'the person living the experience is the source of the information' (Grove, Gray, & Burns, 2015, p. 66). In phenomenology, the researcher is able to observe the lived experiences of the participants, which may reveal certain subjective issues of the participants' lived experiences of a certain phenomenon (Brink, Van der Walt, & Van Rensburg, 2014).

1.6.1. Ontological pre-understandings

Ontology describes the basics of pre-understanding which allow the researcher to define a particular reality (Brink et al., 2014). Ontology clarifies that all participants will experience the phenomena being investigated differently. Being a registered professional nurse with a postgraduate specialisation in nephrology nursing and having experience in working with patients with ESKD, I have an insight into certain pre-understandings regarding the lived

experiences of nephrology nurses in caring for the dying patients with ESKD following the dialysis withdrawal.

1.6.2. Epistemological pre-understandings

Epistemology takes into the context of the pre-understandings that refer to knowledge and truth (Cresswell, 2007). As a researcher and a nephrology nurse, I cannot be detached from the work environment of caring for patients with ESKD. Furthermore, it was anticipated that the nephrology nurses would allow me to engage with them in their work. Being a nephrology nurse, I can bring knowledge of nephrology nursing practices including my experiences of dying and deaths of patients with ESKD.

1.6.3. Methodological pre-understandings

The implication of the methodological pre-understandings is that the researcher studies the topic within context and then uses it to frame a design (Cresswell, 2007). Being at the level of a novice researcher (Benner, 1984), I expected challenges when conducting research using phenomenology, especially due to its 'thick', in-depth and 'vivid' data description and interpretation (Polit & Beck, 2017, p. 595). Another concern was the unstructured nature of qualitative research, especially phenomenology which may impact on me as a novice researcher and my ability to transcribe the rich information of the phenomenology study into text. To overcome this, I reviewed the literature about phenomenology such as the 'Heidegger's early critique of Husserl' by Overgaard (2003), 'phenomenology practice' by Van Manen (2007) and 'qualitative inquiry and research design in choosing among five approaches' by Cresswell (2007). These are explained in more details in Chapter Three (Methodology). Furthermore, I regularly consulted with my supervisor whom has extensive knowledge in phenomenological research.

Chapter Two presents the literature I reviewed to attempt in answering the research question.

Chapter Two

The Literature Review

2.1. Introduction

The literature review in phenomenological research is both complex and confusing for novice researchers, because some authors recommend conducting a full literature examination prior to data collection, while others recommend no literature review at all. Brink et al. (2014) stated that 'in phenomenological studies, the literature should be reviewed after data collection and analysis, to prevent the researcher's openness from being influenced' (Brink et al., 2014, p.72). To make sense of the study, the authors ascertain that after analysing the findings of the study, the results will be compared to the information from the literature to formulate a reasonable argument. This fact is also supported by other authors such as Gerrish and Lacey (2010), who suggested that it is essential that the researcher set apart all preconceived knowledge or ideas on the subject under study, prior to initiating the study.

Lopez and Willis (2004) recommended not to conduct a detailed literature review prior to the commencement of the research study, and this idea is reinforced by Chan, Fung, and Chien (2013) who highlighted the importance of the late literature review in the qualitative research. The authors argue that conducting a literature review after the actual research helps to eliminate the impact of the 'researchers' pre-understanding of the research question' hence preventing their influences on the 'data analysis and collection process' (Chan et al., 2013, p. 3). These authors believe that this fact allows the researcher to achieve subjectivity by continuously ensuring that all biases are neutralised.

Conversely, Humble and Cross in their study on the 'lived experiences of seven veteran psychiatric nurses' have clearly acknowledged that pre-understanding cannot be avoided in nursing research, as it is 'constantly with us in our being in the world' (Humble & Cross, 2010, p. 130). Pre-understandings can be described as the meaning and organization of the culture, languages and practices already existing in the world (Koch, 1995). This author clarifies that

before we understand human beings, these pre-understandings 'are already within our common background understandings and are brought into focus in order to be understood' (Koch, 1995, p, 831). Therefore, pre-understandings, being 'a structure of our *being-in-the-world*', we cannot dismiss it from our mind (Koch, 1995, p, 831).

Boote and Beile (2005) also stated that 'a thorough, sophisticated literature review is the foundation and inspiration for substantial and useful research' (p.3). The authors further stated that good research needs to advance other researchers' 'collective understanding' which can only be done by consulting and 'understanding what was done before, their strengths as well as their weakness' (Boote & Beile, 2005, p. 3). Following this statement, (Allison, 2006), being aware of the constant changes in the nursing and medical practice, has proposed that nephrology nurses consult journals and other scientific fields for information prior to their research. Therefore, being a registered professional nurse with a postgraduate specialisation in nephrology nursing, with six years of experience in working with patients with ESKD and having cared for patients with ESKD, it was impossible for me not to come across literature about caring for patients with ESKD. In this instance, I support the opinion of those authors suggesting a review of literature before commencing the study. As Sir Isaac Newton stated 'If I have seen further it is by standing on the shoulders of giants'(Propova, 2016).

To prepare myself, I consulted literature relevant to the research question and to the methodology in order to highlight the need for the study and to guide the research design. I used the University of Cape Town Health Sciences Library and Information Services and electronic databases such as *Worldcat* and *Worldcat.org*; including search engines of *CINAHL*, *PsychINFO*, *Academic Search Premier* *PubMed* and *Medline* which provided me with journals and peer-reviewed articles. I also consulted the Nursing Academic editorial and google scholar search engines using keywords: '**Dialysis withdrawal, palliative/hospice care in the renal nursing, renal nurses' death anxiety, renal nurses' grief experience**' from 1960 to 2018. The reason for this period is that renal dialysis was developed during the 1940's and 1950's and was utilised as a short-term procedure for patients with acute, life threatening kidney failure

(Russ et al., 2007). It was only in the 1960's that continuous haemodialysis for patients with irreversible kidney function emerged (Fabian et al., 2016; Russ et al., 2007).

The literature reviewed about the research topic is exceedingly limited despite the multiple studies that were done in other critical and oncology nursing specialities. To assist the nephrology nurses to care for patients dying from ESKD it was important to explore their lived experiences in order to understand what 'caring' means to them. The literature relevant to the research question does not offer a conceptual framework for this study, however the caring theories of Watson, Leininger and Life-world Theory will be referred to.

2.2. Nephrology nurses' Human Caring Foundation

2.2.1. Leininger's Theory of Transcultural Nursing

Leininger viewed caring as a 'universal phenomenon' but argued that care may vary according to cultures (Leininger, 1978, p.35). Leininger recommends that nurses seek to understand cultures' 'values, beliefs and daily living patterns' in order to effectively and comfortably practice human caring (Leininger, 1978, p. 7). In line with this statement, patients with ESKD come from different cultural backgrounds and their caring is determined by the meanings and assumptions of the nephrology nurses. The 'professional caring' definition approach of Leininger (1978) states that taking responsibility and providing for people aligns with the caring qualities of Gaut (1983). These dimensions of caring include supportive, assisting and facilitative acts towards the patients according to the specific patient's needs (Leininger, 1978).

Leininger expressed the need to avoid the uncultural norms in nursing which tends to treat all human beings alike to prevent 'favouritism or special considerations' (Leininger, 1978, p. 10). Leininger also believes that all human beings do not necessarily require similar care as their needs might differ according to their cultures, hence she called on nurses to carefully assess the individual patient's 'cultural variations and make differential health appraisals of cultures' (Leininger, 1978, p.10). This is an important point for nephrology nurses caring for

the dying patients with ESKD as the nurses are required to play a role in assisting, supporting and enabling caring behaviours to patients as well as to their families. It is common that when dialysis treatment is stopped, death will follow in a few days, the patient and family may wish to practice their cultural and religious beliefs. For this care to be effective, the nurse should identify the value systems of cultures within the specific family and should display the fundamentals of 'presence, trust, nurturing, compassion, empathy and concern' (Leininger, 1978, p.10).

2.2.2. Watson's Theory of Caring

Watson (1988, p. 7) developed a science structure of 'caring' based on ten carative factors including:

1. The formation of a human-altruistic system of values
2. Instilling faith and hope in patients and their families.
3. The cultivation of sensitivity to oneself and to others
4. The development of a helping-trust relationship
5. The promotion and acceptance of the expression of positive and negative feelings
6. The systematic use of the scientific problem-solving method for decision making
7. The promotion of interpersonal teaching-learning
8. The provision for a supportive, protective, and/ or corrective physical socio-cultural, and spiritual environment
9. Assistance with the gratification of human needs
10. The allowance for existential-phenomenological forces

(Watson, 1988, p. 7).

These carative factors provide nurses with a philosophical foundation which aims at the caring process to help the patient to recover or die peacefully (Watson, 1988). However, Watson

has raised the concern that nursing care is losing its mandate for patient care as the nursing human care role is being jeopardised by 'increased medical technologies' and the 'constraints' of the bureaucratic-management of the institutions in a 'nuclear age society' (Watson, 1988, p. 33).

2.2.3. Life-world Theory and Caring

Hörberg et al. (2014, p. 108) described 'caring' as a science focusing on 'the patient's world and the patient's perspectives in relation to health and wellbeing.' This can be achieved by utilising the *Life-world Theory* introduced by Husserl (Husserl, 1965) and defined by Merleau-Ponty (1996) as '*our being-in-the-world*' or as the way individuals experience their own everyday-life. In the context of ill patients, the *life-world* would mean that the person who suffers that illness is the only one who can describe the experience of that illness (Hörberg et al., 2014). This is in keeping with Galvin and Todres (2009) who argued that even though we all share the commonality of 'being human', we can only partly understand other human beings. Therefore, in order for nephrology nurses to be able to care for their patients, they need to enter into the *life-world* of their patients to get to know them and to know the struggles in their lives, thus helping them to manage their existing issues related to illness (Hörberg et al., 2014).

Bennett found that the creation of the nurse-patient relationship when dialysis is ongoing is different from other nursing specialties. Bennett reported that nephrology nurses and the patients spend a long time interacting with one another, which leads to intimate relationships forming between nurse and patient. Bennett further clarified that this relationship adds to the quality of care provided to the patient as the bond forged is founded on trust, hope and love between nephrology nurses and their patients (Bennett, 2011).

In the 1980s, the concept of 'caring' was brought to the fore (Bush & Barr, 1997, p. 387). Later on, in 1983, Gaut researched the meanings given to the word 'caring' in both scholastic and

lay terms and suggested that the notion of caring includes three major qualities such as (i) , attention or concern for another'; (ii) 'a responsibility for or providing for another;' and (iii) 'a fondness or attachment for another' (Gaut, 1983, p. 314). For Gaut, caring is a word that is 'vague and ambiguous' and its meanings change according to the situation (Gaut, 1983, p.316). Gaut concluded that caring depends on the practical activity and the perspectives associated with attitudes and expectations of those practicing the caring. Morse, Solberg, Neander, Bottorff, and Johnson (1991) agrees with Gaut. These authors reviewed 35 authors' perspectives on human caring and reported that despite a vast number of articles and books about caring in nursing, it is not clear what the definition, components and caring processes are, and that evidence is inconsistent.

The caring concept in nursing was further explored by Parse (1988) and provided three aspects of caring. Parse explained that 'caring' is risking being with someone towards a moment of joy' (Parse, 1988, p.130). During caring, nurses aim to constitute an open and authentic relationship with the patient through which both can grow (Parse, 1988). Parse explained the concept 'risking' in the nurse-patient's relationship as 'being exposed to possible injury' when striving to reach the patient's needs. The author further stated that this could result in the nurse being subjected to possible hurt and rejection (Parse, 1988, p.130). The concept of caring '*being with*' is explained as 'encountering or reflectively attending to the other.' Here the nurses choose to engage with the patient in an open, authentic manner by offering their 'wholeness to the wholeness of the patients' and bearing responsibility to participate with patients in their health-related situation (Parse, 1988, p.131). Lastly, the concept of 'moment of joy' was explained as being the 'complementary rhythm of suffering-joying all at once'. In this context, the Parse clarifies that nurses having been with patients during their 'suffering-joying' stage, allows the patient to grow or prepare for the dying stage, hence both parties move towards a moment of joy and embrace the death stage at the same time (Parse, 1988, p.131).

The acceptance of achieving the final stage of growth may assist the patients and their families to go through the stages of dying as described by Kübler-Ross's 'Dying Stage Theory' (Kübler-Ross, 2009). The author reviewed death as a final stage of growth and provided the healthcare providers with a prospect for healing as different to curing (Kübler-Ross, 2009). She explained that dying people start their dying journey with denial, then anger, then depression, then bargaining and lastly acceptance (Kübler-Ross, 2009). Furthermore, Kübler-Ross stated that the central characteristic in the psychology of dying is hope which is then achieved through a well-prepared grief process which she refers to as a healing care (Kübler-Ross, 2009).

The aim of the curative approach was to treat the disease and eradicate the symptoms, but this is not always possible (Rosa, Estes, & Watson, 2017). Conversely, the authors described healing care as a multidimensional approach which is possible and can occur on the 'emotional, mental, spiritual or physical' platform (Rosa et al., 2017, p. 61). They described death as a 'healing event' which occurs in another non-physical domain of life' (Rosa et al., 2017, p. 61). Rosa and colleagues admitted that through emotional intelligence and empathetic capacity, human beings are capable of 'offering the full range of intimate human caring healing', thus helping the dying person to perceive 'death' as a sense of healing (Rosa et al., 2017, p. 60). This will allow the dying person to view death as a passage to his/her eternal dwelling place as expressed by Hertz (2013), who called death of a prepared patient as the 'passing of the soul to his happy home.' The explanation of caring by Parse rings true for nephrology nurses, as they care for patients with ESKD from diagnosis to death often sharing the good times, socializing with them at parties and other social activities including weddings, birthdays and religious events. However, when dialysis withdrawal decision is taken, the final phase is not always a joy, but rather one of a moral distress as the nephrology nurses are subjected to blame and guilt (Grönlund, Soderberg, Zingmark, Sandlund, & Dahlqvist, 2015).

2.3. Why Do Nephrology Nurses Play a Role as Palliative Care Nurses?

Nephrology nurses care for patients with kidney failure from diagnosis until death, providing care across a life span and health continuum for acute and chronic kidney disease (Zyga et al., 2011). They provide care for patients in diverse settings, including involvement in health promotion and kidney diseases prevention and the management of patients with stage two to stage four kidney failure and dialysis to stage five (Zyga et al., 2011).

Patients with ESKD may be withdrawn from dialysis for reasons of failure to thrive, acute medical illness, dialysis access failure and due to lack of funds (Moosa, 2010; Cohen et al., 2006). In terms of South Africa, being a country with two distinct health sectors, public sector and private sector, withdrawing dialysis may be different. (Etheredge & Fabian, 2017).

In the public healthcare sector, a patient will be withdrawn from dialysis if their condition deteriorates and does not meet the criteria on the assessment. Moosa (2010) explains that as a result of resource constraints, the public healthcare sector had to adopt a rationing guideline for dialysis. The main set criteria to be admitted in the public dialysis program is that the patient must be suitable for kidney transplantation. This means that a patient should not present with any other comorbidities which may impede a kidney graft (South African National Department of Health, 2009). Furthermore, the Western Cape Health Department has adopted a new guideline to which other criteria were added. A patient was scored within three categories (Table 3).

Table 3. Western Cape Provincial Health Selection Categories for Admission to Dialysis Facilities (Moosa, 2010).

CATEGORY 1	CATEGORY 2	CATEGORY 3
<ul style="list-style-type: none"> • Priority for dialysis and transplant program • BMI<30kg/m² • <50years of age • No comorbid disease 	<ul style="list-style-type: none"> • Offered treatment according to resources availability • Transplantation may be unsuitable • Comorbid disease: Diabetes Hypertension Organ damage HIV Hepatitis B 	<ul style="list-style-type: none"> • Offered a conservative therapy. • High morbidity and mortality risk. • Transplantation not beneficial • Severe multiple comorbid diseases as in category 2 • >60 years of age • BMI>35kg/ m² • Active substance abusers or dependency • Liver cirrhosis • Hepatitis B

Those patients who are offered dialysis but later develop any of category 3's conditions are exempt from dialysis. The same applies for patients who have received a kidney transplant and have a kidney graft rejection along with any of category 3's conditions (Moosa, 2010). These selection criteria in the Western Cape, makes it even harder for many patients to fall within the selection criteria especially those who do not meet the age limit and are diabetic. For example, in the SA Renal Registry (SARR) 2013 Annual Report, published in 2015, Western Cape Province had five public renal centres and admitted only 799 patients (160 per centre), compared to Gauteng Province which had six public renal centres and admitted 1023 patients (171 per centre).

Table 1. Comparison of Western Cape Guidelines (2010) with the Department of Health Guidelines (2009) for patients with ESKD admission criteria (SARR, 2015).

Aspects	Western Cape Guidelines, 2010	Department of Health Guidelines before 2010
Principles	Patients must be suitable for transplantation	Transplantation a major criterion
	Guide on modality of chronic dialysis not stated.	Patient and family should be allowed to choose the modality of chronic dialysis
Selection criteria	Both inclusion and exclusion criteria used for selection	Exclusion rather than inclusion criteria applied for selection
Medical	Medical exclusion criteria include active malignancy and advanced irreversible progressive disease of vital organs	Medical exclusion criteria include active malignancy and advanced irreversible progressive disease of vital organs
	Diabetes will be considered below the age of 50 years. Comorbid diseases may be considered	Diabetes and acceptable comorbidity may be considered
	Hepatitis B e Antigen positivity to be excluded	Hepatitis B E Antigen not specified
	Morbid obesity BMI>35 to be excluded	BMI limits not specified
	Age above 60 years are excluded	No age limit stated
Psychosocial	Mental illness with diminished functional capacity as shown by psychiatric and medical examination	Mental illness with diminished functional capacity
	Habitual non-adherence with any medical treatment	Habitual non-compliance with dialysis treatment and lifestyle modification.

For this reason, those patients who are unsuccessful for the public healthcare dialysis admission, must seek treatment in the private healthcare sector if it is affordable. (Etheredge & Fabian, 2017).

In the private sector, dialysis is considered as one of the prescribed minimum benefits (PMB), which means that the private healthcare providers cannot refuse treatment to those members who pay, but the members are also bound to the paying agreement (Etheredge & Fabian, 2017). In addition, the patients are not admitted according to the transplantation criteria but as long as they can afford it (Etheredge & Fabian, 2017). This might explain why the private healthcare sector in terms of dialysis has grown enormously since the introduction of dialysis in SA in the 1960s. However the public sector remains stationary, despite the increase in patients requiring dialysis (Etheredge & Fabian, 2017).

Figure 1 shows the comparative growth in the state and private dialysis facilities in SA since 1994 to 2014.

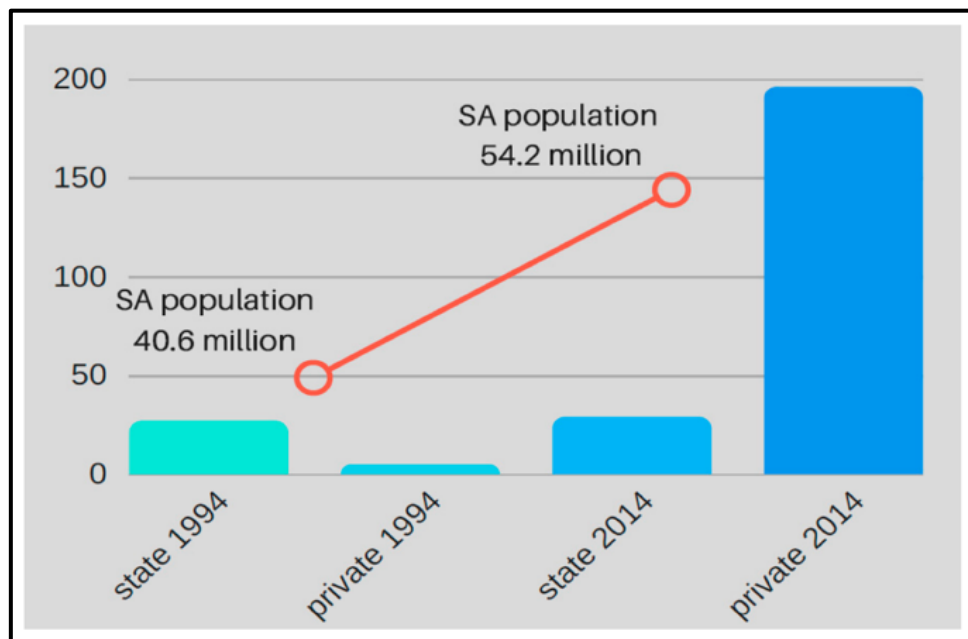


Figure 1. Comparative growth in state and private dialysis facilities in South Africa 1994–2014 (Etheredge & Fabian, 2017).

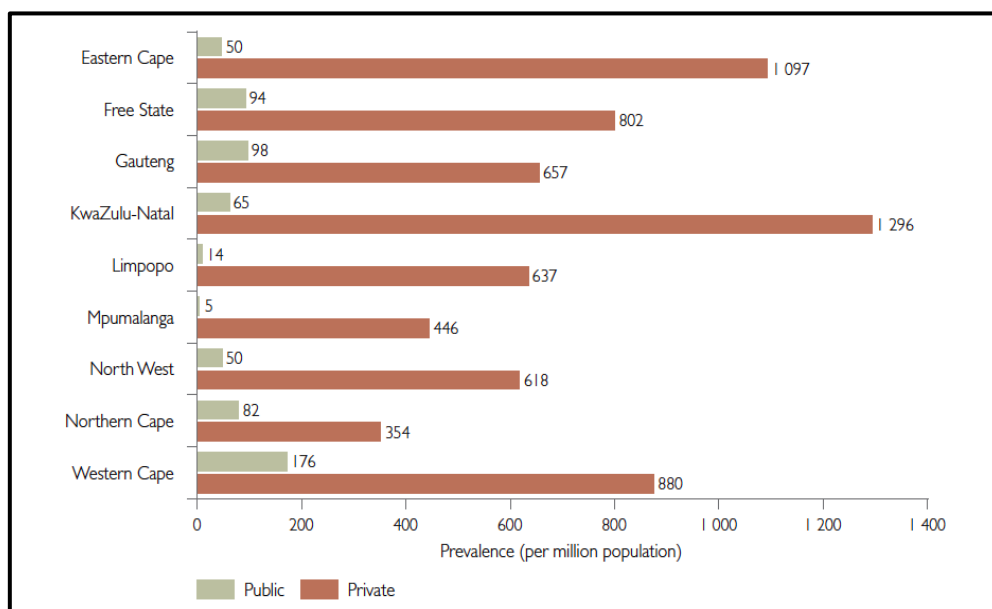


Figure 2. Dialysis and transplantation by province and healthcare sector (South African Renal Society, 2015).

Etheredge and Fabian criticised the SA Government for not adhering to their agreement of delivering healthcare services for citizens (Etheredge & Fabian, 2017). They compared the gross domestic products (GDPs) of developing countries including Bosnia-Herzegovina, Bangladesh and the Philippines, all of which have GDPs lower than South Africa. The authors reported that these countries have managed to provide dialysis to their population at numbers larger than South Africa.

Table 5. Prevalence of chronic dialysis across some upper-middle income countries. (Etheredge & Fabian, 2017).

Country	Gross Domestic Product 1 (Int\$)	Chronic Dialysis(pmp) ²	World Bank Income- Level Classification
Bangladesh	2942	115	Low income
Philippines	6587	221	Lower–middle income
Bosnia- Herzegovina	10,202	691	Upper–middle income
Thailand	15,435	998	Upper–middle income
Columbia	12,725	487	Upper–middle income
South Africa	12,859	719	Upper–middle income
Brazil	15,814	557	Upper–middle income
Serbia	13,772	718	Upper–middle income

The SARR (2015) Annual Report points out that the total number of 719 pmp, 71 pmp were in the public healthcare sector and 648 pmp were in the private healthcare sector. These reports may explain the reason for the lower admission rate compared to private healthcare sector as many patients present with comorbidities and tend to be elderly patients. The depletion of medical and financial support was seen as another reason to withdraw dialysis. This is in contrast to the private healthcare sector where the major reason for dialysis withdrawal is based entirely on the availability of medical insurance and/or finances (Etheredge & Fabian, 2017).

Some studies have emphasised that following a decision to withdraw dialysis, the appropriate supportive care including palliative or hospice care should be provided (Davison et al., 2015;

Fassett et al., 2011). However, the lack of access to palliative care for ESKD has been highlighted in the literature (Gunda, Thomas, & Smith, 2005; A. Johnson & Bonner, 2004; Lohman, 2013; Murray, Arko, Chen, Gilbertson, & Moss, 2006; Soltys, Brookins, & Seney, 1998). In the study carried out by Soltys et al. (1998), of the 14,253 patients admitted to hospice in 1996, only 0,5% were patients with ESKD compared to 4,728 patients admitted in 1995, of which 0,6% patients with ESKD were cared for.

Murray et al. (2006) in a 2-year cohort study reported that of the 115,239 deceased patients with ESKD, 21.8% were withdrawn from dialysis and among them only 13.5% used a hospice. The issue of the lack of palliative care for patients with ESKD in South Africa was also reported by Lohman (2013), a senior researcher working on palliative care issues for the Human Rights Watch. Lohman highlighted that palliative care is more focused on patients with HIV and malignancy than patients with other non-communicable diseases including kidney failure, diabetes, heart and lung disease. The lack of palliative care in patients with ESKD who are withdrawn from dialysis is a concern for nephrology nurses as indicated by Gunda et al. (2005) and Johnson and Bonner (2004). When patients are withdrawn from dialysis, they are referred to the outpatient clinic where they will continue to be seen by nephrology nurses who even at times visit the patient at their homes until they die. Very few of them will have access to hospice care.

This has another negative impact on the nephrology nurses who are already overwhelmed by workoverload and patients' suffering. Böhmert, Kuhnert, and Nienhaus (2011) indicated that caring for patients with ESKD involves intensive and long-term contact with patients who are often frustrated and depressive. The authors also acknowledged that the nephrology nurses experience distress and strain due to the confrontation with suffering and death of their patients, staff shortages and dealing with ever developing highly modern technologies (Böhmert et al., 2011). They highlighted these patients can remain receiving dialysis for many years, making the relationships even stressful. Furthermore, the authors recommended that because of all these factors, which make the dialysis environment specific the results of studies on the occupational stress and strain suffered by other healthcareworkers in other nursing disciplines, cannot be reliably generalised to nephrology nurses (Böhmert et al., 2011).

2.4. Nephrology Nurses Facing the Suffering and Dying of Their Patients.

Nephrology nurses are overwhelmed when facing the death of their patients with whom they have developed a bond and they must care for them knowing that the death is near (Zyga et al., 2011, Moss, 2000). The nurse-patient relationship impacts on nursing care when the patient's conditions deteriorate (Davies et al., 1996). Davies and colleagues have expressed their views for the behaviour of the nurses caring for dying children with threatening life diseases such as ESKD, cancer, cystic fibrosis and premature birth. They reported that after recognizing that the child's death was inevitable, the nurses who developed a close relationship with the dying child, began to withdraw from the child and the family (Davies et al., 1996). The authors further stated that when it became clear that the child was going to die, 'the child's death often conflicted with the reality of the active treatment regimen for the child', which marked the important 'struggle with grief distress and moral distress' (Davies et al., 1996, p.6).

The distress of grief experienced by these nurses was noticeable from the struggle to express their sad feelings as this is frowned upon in accordance with their professional expectation (Davies et al., 1996). Davies and colleagues also reported that nurses who were in close relationship with dying patients demonstrated more grief distress than their colleagues who did not have an existing bond with the dying patients (Davies et al., 1996). The nurses also experienced the moral distress which is explained by their powerlessness over the decision-making regarding the necessary patient care. The nurses felt helpless to perform their duty to ensure the comfortable death of their patients and their families, with whom they had developed a bond (Davies et al., 1996).

The nurses often felt useless, worthless, guilty and helpless as they watched their patients die and were unable to intervene, especially in cases when decision to withdraw dialysis as a result of financial and resource constraints (Castles & Murray, 1979). In the case of dialysis withdrawal, nephrology nurses may experience blame from patients and families and the physicians. In Thomas (2008) study, nurses were scapegoats by the physicians who were

reluctant or failed in continuing basic nursing of their patients when they were faced with this situation that would upset the patient's family. The author further reported that this was one of the factors contributing to the nurses' distress.

Kim et al. (2016), highlighted that nephrology nurses experience the same emotions as nurses as they both care the patients with incurable diseases. Whilst caring for their dying patients, nurses experienced feelings of 'hopelessness, depression, pain, emotional exhaustion, resistance, frustration and feelings of incompetence' as a consequence to their inability to intervene in the progression of the disease (Kim et al., 2016, p. 1460). Their findings support Showalter (2010) who reported that nurses and other healthcare professionals who care for patients and families affected by impending deaths, illness, trauma loss and grief, are overwhelmingly affected by the secondary trauma that they are exposed to daily. Showalter, (2010) reported that healthcare professionals witnessing the suffering of patients and their families whilst unable to intervene until death resulted in them suffering a compassion stress. The author also found that healthcare professionals manifested various physiological and psychological symptoms including depression, withdrawing from family and friends, losing interest in things they once enjoyed, having persistent thoughts and images related to the patient's suffering.

Vermunt and Steensma (2005) also stated that stress occurs among individuals when there is a discrepancy between demands and the individuals' ability to fulfil those demands. The authors admitted that stress leads to further strain particularly if the individuals are exposed to the stressors over a prolonged period. These stressors can be behavioural, psychological and physiological (Vermunt & Steensma, 2005). Furthermore (Showalter, 2010; Vermunt & Steensma, 2005) agreed that accumulated stress also intensified and this result in physical symptoms including aches, pains and muscle tension.

Keeping in mind that death is the last developmental stage, a goal and a fulfilment, nurses find themselves in a state of conflict, as the role of nursing is one of caring and nurturing

(Castles & Murray, 1979). This conflict often arises due to their powerlessness to fulfil that caring and nurturing function which may evoke their feeling that their patient's '*life-world*' was not taken into account (Hörberg et al., 2014). Their inability to take a decision to alleviate suffering of their patients may cause feelings of anger, shame, guilt (emotional trauma) which could develop into post-traumatic stress disorder (PTSD) (Orth & Wieland, 2006). Orth and Wieland define anger as an emotion which is characterised by cognitive, physiological, motivational, and behavioural aspects. The cognitive aspect is the awareness of that 'the important personal goals are blocked by improper action of an external agent, and the motivational component frequently involves hostile and aggressive impulses' (Orth & Wieland, 2006, p. 699). The authors also explained that the emotion of anger is characterised by a hostility component. This was described as an attitude and this was explained as a tendency to hate and distrust others because one tends to take the behaviour of those involved as selfish and cruel (Orth & Wieland, 2006).

The shame concept was described by Wilson, Drozdek, and Turkovic (2006, p. 125) as a 'deeply rooted sense of having violated one's true nature, no matter how accurately or inaccurately perceived by oneself or others'. The authors further highlighted that shame in its extreme forms is a painful and draining experience (Wilson et al., 2006). Bratton (2010) reported that there is a relationship between anger and shame and that these two variables play an important role in a trauma response. Wilson and colleagues further clarified that shame and anger are symptoms of post-traumatic stress disorder. In their study, they explored the reason why some people who suffer from emotional trauma develop post-traumatic stress disorder and others do not. They investigated the three categories of patients. Those suffering from: (i) emotional trauma but with no PTSD; (ii) those with emotional trauma with PTSD and (iii) patients with no emotional trauma. The results revealed that those patients suffering from emotional trauma with no PTSD, reported lower levels of shame than both the control group with no PTSD. In contrast, those presented with a high level of shame were more likely to develop PTSD and were less willing to seek psychological treatment.

The caring relationship with patients and their families was seen as one of dependency which may also be the cause of guilt. The nurses are unable to alleviate the suffering of their patients (Strandberg & Jansson, 2003). In their phenomenological study exploring the '*meaning of dependency on care as narrated by nurses in Northern Sweden*', the authors reported that nurses wanted to do all they could for their patients to maintain that dependency relationship, but they viewed it as burdensome responsibility when they were unable to do so. This evoked the feeling of guilt and inadequacy and of being constantly concerned and worried (Strandberg & Jansson, 2003). This was also supported by Wilson and colleagues who described guilt as 'transgressions or failed behavioural portrayals for responsibilities regarding others, and they suggested that it concerns different forms of self-recrimination about accountability for personal actions' (Wilson et al., 2006, p. 123).

Bratton proposes that the reason why guilt and shame is so painful is that the recovery over time is due to the individual's inability to correct or repair what went wrong which is not possible in many instances (Bratton, 2010). This fact clarifies why guilt and shame may be the major symptoms of PTSD which develops over time, subsequently to the emotional trauma experience/event (Bratton, 2010).

The findings of a Dutch PTSD scale based on DSM-III PTSD criteria, carried out by (Hovens et al., 1993), on the Dutch Resistance Veterans of World War II, guilt was one of the six factors linked with PTSD. The items in the (i) guilt factor were, '*I feel guilty when I think about those people who didn't survive the war*' and '*I feel guilty when I think about the people who suffered during the war,*' and the other factors were: (ii) intrusive memories from the war and sleep difficulties; (iii) physiological arousal; (iv) detachment; (v) rage and (vi) active confrontation of war stimuli (Hovens et al., 1993, p. 200).

The uncomfortable but inevitable situation that nephrology nurses face once a patient is withdrawn from dialysis is that they must experience the phases of dying and eventual death. The patient's body swells and bloats, they struggle to breath and the vital signs deteriorate resulting in confusion and loss of consciousness (Kuebler, 2001). The author acknowledges

that after dialysis withdrawal' the dying process can be a time of emotional crisis for the family members' and recommends that nephrology nurses are expected to be able to deal with their personal feelings about death and dying to be able to communicate with dying patients and their families (Kuebler, 2001). According to Pattison (2008), the nurses are responsible to prepare the family about impending death of their loved one. This preparation is seen as a 'good death' and is based on respecting the patient and family's wishes. Kuebler also stated that when a family is well informed about the prognosis and the outcome of disease, they are better prepared to deal with it (Kuebler, 2001).

However, Zyga and colleagues (2011) study exploring 49 Greek renal nurses' attitude towards death, 22 responded that they were not trained on how to deal with EoLC and death issues - 29 reported never discussing death issues with terminally ill patients (Zyga et al., 2011). Among those who reported to have discussed death issues, eight felt extremely uncomfortable.

Another study of renal nurses carried out in Spain by Ho et al., in 2010 exploring the attitudes towards caring for dying patients also reported that these nurses were confident in providing physical and clinical care to dying patients but demonstrated difficulties in dealing with EoLC from a psychological aspect. In their cross-sectional survey of 202 renal registered nurses in Spain (N=202), 89% (n=180) reported care of a dying patient as an emotionally demanding task; 95.3% (n=93) reviewed addressing death issues as a special skill requirement and 92.6% (n=187) felt that education in death care is necessary. Their findings were in the accord with the study of Zyga and colleagues who also testified that nurses who had a specific training in palliative care experienced less fears of death (Zyga et al., 2011).

The responsibility of all nurses is to focus on offering emotional support to the grieving family Kübler-Ross (2001). This may result in nurses leaving their own emotional needs unaddressed (Zyga et al., 2011). Unaddressed emotional needs were also emphasized by Kübler-Ross who described death as a 'fearful, a frightening happening,' and further explained that 'the fear of

death is a universal fear even if we think we have mastered it on many levels' (Kübler-Ross, 2009, p.4). Castles and Murray (1979), also highlighted that death being 'the end of life and final separation from loved ones, is harder to rationalize (Castles & Murray, 1979, p.23).

2.5. Nephrology Nurses' Experiences of Grief

Following the deaths of their patients, nephrology nurses may suffer from a personal loss because of the prolonged countertransference in the relationship between them and their patients and often the family and other caregivers. This bond is 'a common bond among all mankind and is the reality in the event of death.' Furthermore, Castles and Murray acknowledge that the nurses will experience the impact of death 'more than once, in more than one role and with different intensities' (Castles & Murray, 1979, p.23).

Nephrology nurses may be subjected to grief - a condition defined as a 'response to loss' and this should be followed by the mourning process, known as a 'process of coping with loss and grief' (Hockey, Katz, & Small, 2001). Young (2009, p. 40) defines bereavement as the 'state of having suffered the death of someone significant' and has included in this category the family, and anyone who lives, works or cares that person who died. In this context, Hertz (2013) has stated that to reach the final encounter with any person who has died, there should be a final ceremony to follow. Those who remain after death should 'give a burial to the remains of the deceased,' 'ensure the soul peace and access to the land of the dead' and to 'free the living from the obligations of mourning' (Hertz, 2013, p. 54). The author explained that the burial consists of 'the final resting place of the body', whereby people will sing to beg the souls who are buried there to welcome their new comer. After burial, the relatives and friends depart from the grave site with the feeling that they do not owe the deceased anything. On returning home, they sing and drink to close 'the dark period dominated by death and open a new era' (Hertz, 2013).

Most of the time, nurses are not involved in the process of mourning and bereavement of their patients, as they are not directly related to the patients. Their grief will not be legitimately recognised, therefore they may experience 'disenfranchised grief' (Doka, 2002). Doka explained 'disenfranchised grief as sorrow that is experienced when a loss cannot be openly acknowledged, socially sanctioned or publicly mourned' (Doka, 2002, p. 161). Deprived or avoided grief may later result in psychosomatic symptoms such as physical pain for which the causes are not apparent. Conditions such as peptic ulcers, heart disease, asthma, headaches and other ailments may ensue (Leick & Davidson-Nielsen, 1991). The mourner may also present with some psychological symptoms often attached to an affective picture of sadness, emptiness, anxiety and anger (Leick & Davidson-Nielsen, 1991). There may be phobic behaviour towards anything related to the deceased and a strong dependency upon others or isolation (Leick & Davidson-Nielsen, 1991).

Kübler-Ross stated that 'grief, shame and guilt are not very far removed from feelings of anger and rage and that the process of grief always includes some element of anger' (Kübler-Ross, 2009, p. 4). Rickerson, Somers, Allen, Lewis, Strumpf and Casarett (2005) explored the prevalence of grief related symptoms and the need for bereavement support for nursing staff (N=236) working in long-term facilities in Pennsylvania USA. The nursing staff reported more symptoms were those who experienced more deaths and had worked for a considerably long time in the field developing relationships with the patients who died. The results of this study showed that death(s) affected them on an emotional level (78 %) (n=184), on their relationships with other patients (36%) (n=85), on their own personal and family relationships (26 %) (n=61), and on their relationships with their co-workers (27 %) (n=34).

Summary

The main goal of nursing is to deliver high quality care to ensure a positive and healthy outcome (Soltys et al., 1998). When a decision is made to withdraw dialysis, nephrology nurses are overwhelmed in facing the deaths of their patients (Ashby et al., 2005). The health

and wellbeing of healthcare providers is essential for the delivery of healthcare services and care. Addressing the wellbeing of all nurses may prevent or lessen the ongoing problem of staff falling ill, absenteeism, staff turnover and moral performance all of which have negative sequelae on the quality and delivery of patient care (Ross, Jones, Callaghan, Eales, & Ashman, 2009; Shields & Ward, 2001).

Tranter, Josland, and Turner (2016), have recommended the ongoing education regarding dialysis withdrawal and communication regarding sudden deterioration and death to alleviate fear of deaths and dying among nephrology nurses. The authors also advised to offer the opportunity to these nurses to gain skills in talking openly and compassionately with patients and their families who may be facing dialysis withdrawal due to medical reasons to help to strengthen their ability to cope in this situation(Tranter et al., 2016).

Understanding nephrology nurses' effects of grief and stress when their patient dies and offering death education is imperative to maintain a workforce that is physically and emotionally capable to perform optimally in these difficult working environments.

Chapter Three

Methodology

3.1. Introduction

The purpose of this study was to better understand the nephrology nurses' lived experiences of dying and deaths of patients with ESKD following withdrawal of dialysis, thus qualitative research methodology utilising a phenomenological approach was found to be appropriate research design for this study. This chapter discusses the research methodology and the research design.

3.2. Research design

The research question guides the to determine the research design, data collection and the process of data analysis and methods to be used in a research project (Brink et al., 2014). The goal of this research was to understand the nephrology nurses' lived experiences of caring for the dying patients after dialysis withdrawal. Phenomenological approach is a research methodology which enables the researcher to explore and understand the participants' experiences about a phenomenon under investigation (Brink et al., 2014). By focusing on the events experienced by the participants, the researcher is able to retrieve meanings and develop understandings which further can be developed into 'concepts and themes' (Brink et al., 2014, p. 122). The phenomenological approach is known as an inherent philosophical component based on phenomenologists such as Husserl, Merleau-Ponty, Heidegger, Van Manen, Giorgi and others (Cresswell, 2007).

The philosophy of phenomenology begins in the original real world of a person's everyday life experience (Van Manen, 2007). Phenomenology is described as a method of inquiry which is appropriate and suitable to gain a deep understanding of an individual experiencing a particular phenomenon within their everyday world (Cresswell, 2007). In addition, Munhall (1994) explained that phenomenology may be seen as an approach to understand human beings and what their life experiences meant to them, rather than being a mere method of

research. In this study, the I engaged with the participants in the phenomenological conversations and made field notes of observations which were used to constitute the narratives of the participants.

To get more clarity on the phenomenological approach, I also followed the explanation of phenomenology by Gerrish and Lacey (2015, p. 2011), who clarified that the aim of phenomenology is not merely to explain human behaviour conferring to the universal laws. The authors explained that this type of research methodology seeks to understand the individual's subjective experience which cannot be adequately replaced by any external analysis or explanation (Gerrish & Lacey, 2015, p. 2011). This made me to understand that the lived experiences of the participants' everyday world of caring for their patients with ESKD after dialysis withdrawal could be revealed through their consciousness and presented in many forms as elaborated by Pascal (2010). Pascal expresses that in nursing research, phenomenology is useful as it allows the participants to describe their experiences regarding a phenomenon. In this case, *the lived experiences of nephrology nurses caring for dying and the deaths of patients with ESKD, following withdrawal of dialysis*. In doing so, their experiences may build upon an understanding amongst healthcare providers about the participants' experiences of dying and death. These experiences may offer an opportunity to address the emotional and educational needs that nephrology nurses require to care for themselves and the patients with ESKD, who are in the process of dying or have died following withdrawal of dialysis.

Elaborating on the literature regarding phenomenology, I, further understood that, there are two main approaches to phenomenology; interpretive (hermeneutic) and descriptive (Gerrish & Lacey, 2015). These two research approaches differ accordingly to how they are used and the philosophical foundations of the intended studies. Descriptive phenomenology (Husserlian Epistemology) aims to describe and clarify the nature of the phenomenon 'in a broadly traditional, normative and scientific sense' (Finlay, 2011). In Husserl's work '*Logical Investigations*' (1970), he described the structure of experiences and how they are given in '*consciousness*' without attempting to interpret the meanings (Finlay, 2011). Also, in

descriptive phenomenology, it is essential that the researcher set apart all preconceived knowledge or ideas on the subject under study, also known as '*bracketing*' (Gerrish & Lacey, 2010, p. 181). For this reason, (Lopez & Willis, 2004) recommended that the researcher using this form of methodology, should not conduct a detailed literature review prior to the commencement of the research study. Their argument is that this allows the researcher to achieve subjectivity by continuously ensuring that all biases are neutralized (Gerrish & Lacey, 2010).

Interpretive phenomenology (Heideggerian Ontology) or more accurately, hermeneutic phenomenology, derived from Heidegger, 'a one-time assistant' of Husserl who challenged the descriptive nature to phenomenology (Overgaard, 2003, p. 157). Heidegger in his opus, '*Being and Time*' (1962), argues that it is critical to understand the life's experiences of individuals in order to interpret the concealed meanings confined in it (Lopez & Willis, 2004). Flood supports Lopez and Willis by explaining that 'what people experience rather than what they consciously know' is phenomenology (Flood, 2010, p. 9). Heidegger tested the descriptive without the interpretative approach of Husserl and emphasized that the essential factor in hermeneutic phenomenology is to understand the association that the participants have with their life-world (Gerrish & Lacey, 2010). Heidegger referred to the concept of '*life-world*' as the impact and influence that the environment can have on one's life and highlighted further that human beings cannot live in isolation in this world (Heidegger, 1962). There is a degree of interpretative flexibility in following the hermeneutic approach of inquiry (Gerrish & Lacey, 2010). This explains that the way individuals experience their everyday life is linked to their 'work, culture, social life and relationships with people that they interact with' (Lopez & Willis, 2004, p. 729). This also explains the reason as to why the hermeneutic phenomenology has no correct or incorrect interpretation.

The source of the findings in hermeneutic phenomenology is based on the interpretations of the narratives or stories provided by the participants. These interpretations are further scrutinized and can often be challenged by both the participant and the researcher. It is crucial to note that the pre-understandings in this context is that the knowledge (epistemology) and

experience (Rosa et al., 2017) of the researcher acts as important guides to the research process. Heidegger stressed that 'it is impossible to rid the mind of the background of understandings that led the researcher to consider a topic worthy of research (Flood, 2010, p. 10). This fact of hermeneutic phenomenology is in contrast with the idea of the '*bracketing*' approach recommended by Husserl (Lopez & Willis, 2004).

Mackey (2005) emphasized that understanding the hermeneutic phenomenological approach makes it more likely to reveal the diversity and the depth within nursing knowledge. Through the hermeneutic phenomenological approach towards gaining knowledge, the researcher is able to conduct an appropriate data (information or material) and analysis (unravelling). This may reveal authentic findings and pedagogical offerings in addressing the nephrology nurses' experiences of patients dying with ESKD. Finlay (2011) asserted that the researchers' personal history, experience, knowledge and understanding leads them into the research and guides them toward the research process. In this context, I, the researcher, am a registered professional nurse with a postgraduate specialisation in nephrology nursing and have five years' experience in working with patients with ESKD. In addition, I care for the dying patients withdrawn from dialysis and thus found it nearly impossible to bracket in this research process. Therefore, the interpretive approach was found to be more appropriate for this study.

3.2.1. Paradigm

To understand a phenomenon in its entirety, a qualitative research method using a phenomenological approach with an interpretive stance was used. To achieve this, it was important to describe and interpret the information provided by the participants about their experiences. These lived experiences included practical experiences, knowledge and emotions. In interpretive phenomenology, 'an intersection' of the experiences of both the researcher and the participant is essential as part of the research process (Holloway & Wheeler, 2010, p. 228). Flood states that 'understanding and getting to know others is based on a personal horizon of experiences and meanings' (Flood, 2010, p. 10). In this study, my

experiences of working with dying and deaths of patients with ESKD, results in being related to the phenomenon under investigation. These experiences strengthened the understanding of the lived experiences of the participants and facilitated the interpretation, thus resulting in a rich and meaningful data (Pascal, 2010). Being a novice researcher (Benner, 1984), I have engaged with the supervisor of this study to use the language of phenomenology which is unique to both the philosophy and the methodology (Table 6). I also acknowledge the methodology of interpretative phenomenological analysis (IPA) which is used to explore idiographic subjective experiences and social cognition. This is known as the theoretical underpinnings of IPA stem from Husserl's phenomenology and Heideggerian hermeneutics and symbolic interactionism. As a novice researcher, a phenomenological approach with an interpretive 'leaning' is deemed appropriate for this research study. Therefore, IPA was not used and there is no philosophical underpinning to the study. Table 6 explains the language of Phenomenology used in this study.

Table 6. The Language of Phenomenology.

QUALITATIVE & QUANTITATIVE RESEARCH TERMINOLOGY	PHENOMENOLOGICAL 'LANGUAGE'
In phenomenological research, methodology and method(s) are separate concepts. Methodology pertains to the philosophical framework and underpinnings that inform the method to be used and method refers to the procedure for carrying out the research.	
Assumptions	Pre-understandings. Can also use pre-conceptions. Must include ontological, epistemological and methodological
Recruitment of subjects/informants	Invitation of participants
Semi- structured interview/tool	Phenomenological conversation
Data collection	Information/material gathering
Data	Phenomenological texts or narratives
Data analysis – coding, sorting	Information/material unravelling
Data saturation	Hale, Treharne and Kitas argue 'that true data saturation can never really be achieved' because each individual's experiences are so unique (Hale, Treharne, & Kitas, 2008, p. 91). 'Richness of information/material
Formulation of themes	Unravelling of lived experience themes to capture the essence or meaning and authenticity

3..3 Population

The research population were the registered nurses working in selected two private renal care units in the Cape metropole area. These dialysis centres offered both chronic haemodialysis (HD) and peritoneal dialysis (PD).

3.3.1. Study Setting

The phenomenological conversations were conducted in the training rooms in the study setting and a sign indicating '*interview in progress, please do not disturb*' was displayed on the doors to ensure privacy and non-interruption of the phenomenological conversations. Being employed by the dialysis provider company for five years allowed easy approval of the use of these facilities for the research purposes. The access to these units was obtained in the informal and formal ways. Firstly, the permission to conduct this study was sought by submitting the research proposal to the Faculty of Health Science Human Research Ethics Committee which was granted. Furthermore, the approval from the dialysis provider company (Appendix D) was granted by submitting the research proposal and the approval from the Faculty of Health Science Human Research Ethics Committee. Secondly, the informal way to access the research sites was negotiated with the operational and the unit managers as well as the dialysis personal.

3.3.2. Sampling Method

A purposive sampling method was used to recruit the registered nurses working in two selected private renal care units in the Cape metropole area. In qualitative study design, the sample had to be adequate and appropriate for the study's aim (Holloway & Wheeler, 2010). For this reason, the sampling decisions are based on a systematic basis and on rational grounds (Holloway & Wheeler, 2010). Acknowledging the above consideration, I employed a purposeful sampling method and personally invited the registered nurses, working in the research setting.

3.3.3. Invitation of Participants

Once approval was received to commence the study, the Operational Managers of the research setting were officially approached for permission to gain access to the dialysis units. A meeting with the staff was arranged to tell them briefly about the study and left the contact details for those interested, who wished to participate in the study. The potential participants, (those who have responded and who met the inclusion criteria), were invited and full disclosure was given regarding the purpose and aims of the study. An information sheet was provided, allowing the participants enough time to read and ask questions to ensure that they understood all concepts of the study. The participants were reminded that their participation was voluntary, and that they may withdraw at any time without being subjected to a penalty or prejudice. The phenomenological conversations were conducted in a suitable venue in the study setting and, in the participants' convenient time, ensuring privacy and non-interruption of the phenomenological conversation.

3.3.4. Sampling Criteria

Purposive sampling allowed the researcher to select the participants with knowledge of the phenomenon of the study (Brink et al., 2014). The participation of the registered nurses was voluntary, and permission was obtained from the relevant managerial and administration departments of the two institutions for access to the study settings. To gain the richness and in depth-account of their experiences, I ensured that suitable participants were invited as per inclusion and exclusion criteria.

3.3.4.1. Inclusion Criteria

- The participants had to be working in renal care unit at the research setting for at least six months.
- The participants who have cared for dying patients with ESKD following the dialysis withdrawal.
- The preferred language for the phenomenological conversation was English.

As a novice researcher, it was imperative that the transcribing be done personally and not through a translator. Using a phenomenological approach, the essence of the participants' narratives can be misleading and ambiguous if a translator is used.

3.3.4.2. Exclusion Criteria

- The permanent nephrology nurses who were on leave at the time of the study.
- The agency nephrology nurses.

3.3.5. The Sample Size

The sample size were eight participants who met the inclusion criteria. In-depth phenomenological conversations of approximately 45 - 90 minutes were used to gather in-depth personal accounts of the nephrology nurses lived experiences. I planned to purposefully interview six to ten nephrology nurses and stopped at the ninth participant, as it was noted that the information provided was a repetition and this was seen as richness of information (Burns, Grove, & Gray, 2015). Those who completed the study were eight participants (n=8), as one could not be reached for the feedback session, therefore the information provided by this participant was not used in this study. The participants' demographic information was collected in the course of the phenomenological conversations,

but it was omitted to maintain their anonymity. The participants' age range was between 36 and 58 and included six females (n=6) and 2 males (n=2). Their years as a registered nurse ranged from 6 -40 and their experience of working in the renal care ranged from two to ten years. In term of race, five of them were Coloured (n=5), one White and two African (n=2).

3.4. Ethical Considerations

During this research process, I adhered to the ethical principles of the Declaration of Helsinki (World Medical Association, 2013). Throughout this study, I was guided by this principle to promote and safeguard the health of the participants, making sure their well-being is the priority. Before commencing the study, I have obtained the Ethical Clearance from the Health Sciences Research and Ethics Committee at the University of Cape Town (HREC 401/2017) (Appendix E). I also obtained permission for the study sites access from the dialysis providers of the selected private renal care units (Appendix D). The participants signed written consent for the initial phenomenological conversation and all feedback sessions (Appendix).

3.4.1. Informed consent

Brink et al. (2014) emphasized that it was mandatory to get an informed consent from the participants before commencing the research as this is the way to respect their autonomy. Applying the principle of respect for autonomy allows the researcher to be assured that the participation is voluntary and the participants understand the benefits of the research and the potential risks they may encounter (Brink et al., 2014). I have provided to each participant an information sheet (Appendix A), clarifying the purposes of the study. The consent and information sheets were written in a simple English as all the participants were comfortable with English language. The participants were given enough time to read and understand the contents in the information sheet and consent forms, and their voluntary responses to participate ranged between 2 days to a week.

Prior to signing the consent, I provided the information to each participant regarding the nature of the research, its purpose, the potential benefits to the participant as individual and to the nephrology nursing as a profession, as well as to the patients and their families as a society. I also took a time to explain to each participant, the implication of signing the consent to participate to the study and the right to withdraw any time without any penalty or any other consequences. Confidentiality was assured to all the participants and all were given the opportunity to ask questions regarding the study. Being aware of the complicated nature of the qualitative research, due to its natural flexibility and unanticipated ideas during data collection, the participants were made aware that the informed consent in qualitative study is not a once off agreement, rather an ongoing process as the study progresses (Brink et al., 2014). Therefore, the informed consent was re-obtained prior to the second phenomenological conversation (feedback sessions) with each participant.

3.4.2. Autonomy

The principle of autonomy was adhered to as the participants were given the right to decide to participate in the study and to withdraw any time, without the risk of being punished or face prejudicial treatment (Brink et al., 2014). This issue was clarified to the participants in the information sheet and informed consent which provided the research project, the aims and objectives of the study.

3.4.3. Benefits and Risks/Vulnerable Participant Protection

I have clarified to the participants that they would not directly benefit from the study. Furthermore, I anticipated that there would be no physical, spiritual, social economic or legal intervention that could cause harm to the participants. However, as this study was exploring certain lived experiences of participants using a qualitative research approach, risk of exposing unresolved issues (Brink et al., 2014), and psychological or an emotional distress from participants was predicted. In this case, I planned to refer the participant to the

Independent Counselling & Advisory Services Southern Africa Ltd (ICAS) for a debriefing session. The ICAS was the referral choice as the Renal Care Service Provider Company has recommended them as their employee well-being support service. The participants were informed about the planned referral system and to prevent this, a debriefing session was conducted at the end of every phenomenological conversation.

3.4.4. Privacy and Confidentiality

I, the researcher, had the responsibility to explain to each participant that he/she had the right to determine the extent to which his/her private information could be shared or protected from others (LoBiondo-Wood & Haber, 2010). In this study, as I had to be in direct contact with the participants in conversation, it was difficult to keep their identities protected from me. Thus, there was limited confidentiality but total anonymity. The identity of all participants was protected for the research study by using pseudonyms of their choice. Only me, I had access to the audio-recordings and the information transcription, which were stored in the files in my password protected computer. The hard copies of information gathered during the conversations were stored in the locker for which the key was only held by me. The participants were informed that all the audio-recordings and transcribed conversations and any other related information gathered for this study was to be destroyed after five years.

3.4.5. Use of Audio-Recorder Equipment

Before using the audio-recorder, I ensured that the participant confirmed to have read and understood the information on the information sheet regarding the purpose of the study. Each participant signed the consent form and agreed to use the audio-recorder. Following each conversation, the digital file was created in my computer, dated and given a name as the pseudonym of the participant. This process was also applied during the second phenomenological conversations.

3.5. Information Material

The phenomenological conversations were audio-recorded only to protect the identity of the participants in two selected private renal care units in the Cape metropole area.

3.5.1. Trial Run of Phenomenological Conversation

The leading phenomenological question and conversational probes were 'tested' by having the study conversation with one registered nurse, who was not part of the study. This is a colleague who is employed elsewhere. The purpose of this exercise was to test the research methodology and the phenomenological conversation guide before commencing the actual study. The trial run participant asked to clarify whether the questions are clear and understandable for the study objectives. Information obtained was analysed and reported to the supervisor and the phenomenological conversation guide was found to yield the information needed for this study.

3.5.2. Gathering of Information Material for the Study

The phenomenological conversations were audio-recorded to allow me and the supervisor to listen to it numerous times and to enable the information to unravel. To ensure the inclusivity of all the potential participants, I had selected the English based institutions in which all employees spoke English. Therefore, English was the chosen language for both me, the researcher and the participants.

The conversations were held during the lunch breaks, as indicated by the participants to be the most suitable time for them. The participants were not keen to have the conversations when on duty, to prevent the disruption of patient care and would not do it on their day off,

as this is their only time to do their personal and family activities. I identified venues which were suitable so that there were limited interruptions, in order to remain focused during the conversations and to ensure privacy.

The unit managers were informed that I would be there in order to allow the staff to participate in the interview and make use of the venue. I reported to the unit manager before commencing the conversation with the participants. The participant was given an opportunity to sign a voluntary written consent on the day of the conversation. The conversations were audio-recorded, and the participants were only addressed in their chosen pseudonyms and the names of their institutions were not mentioned in order to protect their personal identity and ensure anonymity.

I personally conducted a one-on-one conversation using my phenomenological conversation guide in which the participants were encouraged to share in their own words, their lived experiences of caring for dying patients with ESKD after dialysis withdrawal. The conversations were planned for 45 to 60 minutes with each participant, however, some of them were extended to 90 minutes for me to gather an in-depth information. I entered into my journal my thoughts and reflections which also allowed me to summarize the information from each participant and to reflect on the messages to understand what they really meant. I also had an opportunity to practice these techniques during the trial run phenomenological conversation. The conversation guide was related to descriptions of the experience of caring for the patients with ESKD dying after dialysis withdrawal and focused on the objectives of the study. The conversations were initiated by an open-ended question such as *'Tell me, in your own words, your personal experience regarding caring for the dying patients with ESKD after withdrawal of dialysis?'* During the phenomenological conversations, field notes of observations noticed during the conversations were made, which were also used as information.

I then re-engaged with the participants further in a second phenomenological conversation. This is referred to as participant feedback or member checking in which the interpretations and inferences were returned to the participants for authentication and critique. Member checking enhances the rigour of phenomenological research (Brink et al., 2014). Following the phenomenological and feedback session, I did a reflective journal entry to capture my own personal experience of the conversations and the participants' narratives as revealed below.

Journal entry, 29/08/2017

The forth phenomenological conversation is now completed. At the beginning of the interview, the participant seemed to be relaxed, but as we delved deeper into the conversation, her emotions were evoked, and she became teary-eyed and at times was frustrated. Beauty understood the questions and gave me her genuine experience of caring for the dying patients after dialysis withdrawal. Beauty found it frustrating, dealing with her patients and their families after dialysis withdrawal. This was especially true when she had to tell her patient, who was suffering from short breath and a swollen face to wait in the wheelchair, while negotiating a free dialysis session with the doctor. Beauty mentioned that often the negotiation for free dialysis session was unsuccessful and she did not know how to say 'no' to her suffering patient. With all my phenomenological conversations that I have conducted, I too am faced with the emotional trauma that the participants are experiencing. This topic is not easy, I feel as death's emotions are getting heavier on me, but somehow, I feel absorbed in these conversations and I am determined to remain focused.

3.6. Information Unravelling

'Data analysis is a rigorous process' consisting of unravelling the information in order to make sense or understanding of the meaning of the phenomenon (Grove et al., 2015, p. 88). With regards to qualitative research, this process implies the reduction of information into categories and themes for data analysis and interpretation (Brink et al., 2014). 'This process

requires a discipline to develop a data analysis plan which is consistent with the philosophical method of the study' (Grove et al., 2015, p. 88). The seven-step phenomenological analysis described by Colaizzi (1978) was found to be appropriate for this study. These seven steps are as follows, (1) 'reading all interview data; (2) extracting significant statements; (3) formulating meanings; (4) organizing aggregated meanings into themes; (5) integrating study findings; (6) formulating the description of investigated phenomenon; and (7) validating findings via member check (Colaizzi, 1978)

3.6.1. Transcription

The conversations needed to be interpreted as accurately as possible so as to represent the narratives of the participants. (Holloway & Wheeler, 2010). To be immersed in the information and information unravelling preparation, I personally transcribed the first eight phenomenological conversations within 72 hours of each conversation. It was time consuming, but it allowed me to immediately connect with the information during the learning process. After the first phenomenological conversation, I requested that the participants authenticate my interpretation of their narratives and clarify issues which were raised during the transcription. As a novice researcher I found the second phenomenological conversation (participant feedback) to be important. During the transcription phase, I noticed that some of the information I had captured was unrelated to my study which Holloway and Wheeler (2010) state is a common occurrence.

3.6.2. Unravelling and Interpretation of Information

All phenomenological conversations were digitally audio-recorded and repetitively listened too, before transcription took place. I arranged the audio recordings and field-notes in the files which were named and dated. During transcription, I left a margin for coding, themes and theme cluster categorization. The transcription included the voices, pauses, abnormal body movements and laughter of the participant. In the information unravelling process,

transcribing the information into a practical format i.e. from the phenomenological conversation to transcripts was essential (Brink et al., 2014).

I followed Colaizzi's seven steps as follows:

1. I repeatedly read all the participant's transcripts to attain a feeling for them and make sense of them. Having understood the meaning, I then moved to the phase of coding by writing down the word or phrase more or less similar to the meaning of the information. For instance, when a participant mentioned "*emotional moments*", the code was "*emotions*." To maintain consistency and easy tracking on the multiple transcriptions, I used different colours for each code.

2. During this step, I returned to the transcript of each phenomenological conversation and highlighted the phrases that were directly relevant to the research question. This process is referred to as extracting significant statements (Polit & Beck, 2017, p. 541). In this phase, I referred to specific phrases within the transcripts, for example – **Beauty** said: '*Caring for these patients created a bond between nephrology nurses and the patient, such that it became too emotional for the nurse to detach themselves from the patient when withdrawn from dialysis,*' and **James** said: '*It is emotionally draining, it provokes your emotions. I am still angry for her death because of this selection criteria system.*' I also attempted to visualize the participant's reactions made during the conversation.

3. During this step, I tried to derive the meaning of each statement in the phenomenological conversations and derive insight on its significance, known as 'formulating meanings' (Polit & Beck, 2017, p. 541). Two significant meanings were derived: (a) the '*emotional effect*' and (b) the '*anger effect*.' The nurse-patient bond during patient care eventually ended in frustration when the nurse was unable to provide the normal care that was necessary to relieve the patients suffering. The anger was highlighted by the participants when they realized how patients were abandoned because they did not meet the selection criteria. At this stage, it was deduced that the participants' narratives revealed that they endured high level of emotions after dialysis withdrawal, which was a significant part of this study.

4. In this step, the formulated meanings were organized into theme-clusters which were then organized into sub-themes and then further organized into main themes. The themes clusters, sub-themes and main themes which I decided upon were authenticated by myself and my supervisor. We discussed the similarities and differences together until we reached a consensus on what to include.

5. During this phase, I grouped the results into a detailed description of the phenomenon under investigation. I firstly organized the descriptions in theme clusters and then into sub-themes. For example, the experienced emotions were marked by anger, distress and hopelessness.

6. Here, I once again condensed an in-depth description of the phenomenon under study into a single statement which was a main theme of the participants' lived experiences of caring for the patients with ESKD, following dialysis withdrawal. For example, main theme 1: *Emotional trauma*. Sub-themes identified: psycho-social effects, physiological effect and occupational stress effects. I followed this process to identify another three main themes and sub-themes.

7. This phase involved checking and validating. To adhere to this principle, I returned to the participants with the identified main themes and sub-themes and confirmed these with them. My interpretation of their lived experiences of caring for the dying patients following dialysis withdrawal was discussed with the participants individually and authenticated for validation. To ensure the validation and scientific rigor of data in qualitative research, I used trustworthiness as recommended by Holloway and Wheeler (2010).

Following the Colaizzi's (1978) seven steps of data analyses, the theme clusters, sub-themes and final main themes were generated (Table 7).

Table 7. Theme clusters, sub-themes and main themes

THEMES CLUSTERS	SUB-THEMES	MAIN THEMES
<ul style="list-style-type: none"> • Witnessing unrelieved patient's suffering) • Moral distress • Hopelessness • Insomnia • Fatigue • Difficulty concentrating and withdrawal from social engagement • Aches and pains and muscle tension • Scapegoat and finger pointing • Exclusion from decision-making • Self-expectation and reality. 	<p>Psycho-social effects</p> <p>Physiological effects</p> <p>Occupational stress effect</p>	<p>Emotional trauma</p>
<ul style="list-style-type: none"> • Personal detachment • Professional detachment • Letting go • Fear of being hurt • Avoidance 	<p>Nurse-patient detachment</p> <p>Nurse-family detachment</p>	<p>Detachment</p>
<ul style="list-style-type: none"> • Patient's finance • Manpower • Facilities • Constitution and patient's rights • Nurses' Scope of Practice and patient's care 	<p>Resource constraints</p> <p>Compromised provision of patient care</p>	<p>Loss of altruistic values in nursing</p>
<ul style="list-style-type: none"> • Severing of umbilical cord • Emotional support needs • Unfinished business • Ontological confrontation 	<p>Watching and waiting</p> <p>Re-living the event of death</p>	<p><i>being with death</i></p>

3.7. Trustworthiness

Trustworthiness in qualitative research is described by Holloway and Wheeler (2010, p. 302) as 'a methodological soundness and adequacy' which encompasses dependability, credibility, transferability and confirmability of the research study. Lincoln and Guba Lincoln and Guba (1985) have added authenticity as another principle to evaluate trustworthiness.

3.7.1. Dependability

Grove et al. (2015, p. 392) defines dependability as 'a documentation of steps taken, and decisions made during analysis.' Holloway and Wheeler (2010, p. 302), proposed that for the findings to be dependable, they must be consistent and accurate based on an audit trail. This will help an independent coder to test the dependability and consistency of the study by analysing the collected data independently and comparing the 'information, the results, interpretations and recommendations against those provided by the researcher' (Holloway & Wheeler, 2010, p. 302). For the research to be recognized as reflecting reality, I confirmed that the study results were supported by the documented information. Holloway and Wheeler (2010), also explained that to reflect dependability of the data, the researcher provides an accurate outcome trail which allowed the reader to review the measures, effects and actions that the researcher engaged throughout the research process. In this study, I ensured dependability and consistency by providing an exhaustive description process of the methodology and the use of reflective journals and field notes.

Extracts from My Reflective Journal 19/09/2017

Another genuine phenomenological conversation. Participant is worried whether the situation of dialysis withdrawal due to lack of funds, will ever end. Participant is also worried about patient care, because nephrology nurses tend to listen less to patients in order to prevent

attachment. Participant is concerned about the reduced patient care when the nephrology nurses rather focus on the machines than on the patient.

The participant honestly shifts blame from the private sector to government because it is in charge of the public. Participant is also worried about nephrology nurses leaving the career and mentioned that this nursing care specialty is too demanding, overburdened with many responsibilities and limited support. Participant claimed that this is one of the reasons why they change careers. Participant mentioned having a good family support, but not employment support and said that the ICAS provided by the company is not effective because of the nature of phone calls and the insufficient time as you must return to work due to a shortage of staff.

9/11/2017

The participant demonstrated anger regarding her patient's situation and believes that the death of her patient should have been prevented if there was sufficient money involved. Participant is still living with these emotions, even though she claimed to let it go as was evident by her speech and behaviour during the interview. The participant claimed to rather follow the institutional policy than patient care, which forced them to compromise on their nursing oath of patient 'care. It is a difficult topic to research; the resources are a major problem in the renal diseases. I wish I was a superhero to pay for these patients and to keep our nephrology nursing staff satisfied. This participant also claimed to not be having enough time to mourn for her patient's death. They live with the sorrow and the empty feeling daily as they never got to say goodbye to their patient and terminate existing bonds.

3.7.2. Credibility

Credibility is viewed as the 'confidence of the reader about the extent to which the researcher has produced the results that reflect the views of the participants (Grove, Gray, & Burns, 2015, p. 392). In this study, peer review was done through my research supervisor who also assisted

me with the information unravelling process and the formulation of sub-themes and main themes. The credibility was attained by the participants' authentication of the identified main themes and sub-themes of their lived experiences during the feedback sessions. To achieve credibility, I acknowledged the sensitive nature of this topic and maintained a trusting and private space with the participants to develop a good relationship with them. This rapport allowed the participants to reveal the hidden realities and they felt free to share their sensitive information, making the findings more credible (Holloway & Wheeler, 2010). During the conversation, I used my thoughts to probe and to build upon their experiences to get in-depth information. I also kept my thoughts and feeling regarding the participants lived experiences through journaling and field notes. This process kept me focused on answering the research question. This is in line with Grove et al. (2015), who highlighted that the researcher's self-understanding is significant in qualitative research, as this facilitates the interactive process between the participant and the researcher (Grove et al., 2015).

In this study, I established credibility by adhering to the following:

- I kept a reflective journal and field notes taken throughout the research process.
- The unravelled phenomenological conversation transcripts were discussed with each participant for authentication. The participants approved the formulated main themes and sub-themes and the interpretations in relation to their narratives.
- My research supervisor assist me with the unravelling of the phenomenological conversations and the formulation of merging of themes.

3.7.3. Confirmability

Brink et al. (2014, p. 126) defined confirmability as 'the potential for data to be accurate and meaningful'. This signified by an audit trail that enabled the reader to trace the source of information (Holloway & Wheeler, 2010). This concept further enables the reader to logically follow a pattern of reasoning in which the findings and conclusions are achieved and confirmed such that the results was not biased.

To ensure confirmability I used two techniques as recommended by (Brink et al., 2014). These included the triangulation of the information and the audit trail. Triangulation is the 'use of multiple methods or perspectives to collect and interpret data about some phenomenon or to converge on accurate representation of reality' (Brink et al., 2014, p. 218). In this study, I looked at the same phenomenon from different perspectives and from diverse angles, using 'member checking' or 'participant feedback' to authenticate collected feedback from participants (Brink et al., 2014, p. 172). Here, with the use of leading question and probes, I encouraged the participants to remove errors to avoid misunderstanding or ambiguity and provide additional information.

3.7.4. Transferability

Holloway and Wheeler (2010) explain that transferability is the ability to apply the findings to other similar situations and/or to participants. The intention when using phenomenology is to describe or interpret the unique lived experiences of participants who share a phenomenon under investigation (Brink et al., 2014). Therefore, the definition of transferability might not be appropriate to my study as it focuses at the present situation. Also the focus of qualitative research is not to generalise the findings but rather to describe 'the observations within the specific contexts in which they occur' (Brink et al., 2014, p. 173). Therefore, the findings in my study may be transferred to similar situations in one context, and within another context or may be similar to the findings of other studies exploring this phenomenon. The appropriateness of the findings in my study was established by providing in-depth descriptions of the information and is presented in detail in Chapter Four.

3.7.5. Authenticity

Authenticity refers to the degree to which researchers fairly and faithfully demonstrate a variety of diverse realities (Polit & Beck, 2018). The authors argue that the authenticity occurs from the participants report when it reflects the feeling tones of their experiences. During the phenomenological conversations, these realities were revealed and captured in my reflections. I kept a reflective journal and field notes taken throughout the research process which guided me in developing a report of their own lived experiences. Furthermore, I discussed the transcripts with each participant in the second phenomenology conversations. This phase created another platform whereby the participants felt more aware of the phenomenon and had more insights to ask questions regarding the study and what could be the answer to deal with this situation.

The participants approved the formulated main themes and sub-themes and the interpretations in relation to their narratives. This is in accord with Schwandt, Lincoln, and Guba (2007) who clarified authenticity being an extension of the trustworthiness criteria because it allows questions to be asked about the process of interpretations and the way this process has progressed. The authors also emphasised that authenticity principle acknowledges that inquiry and understanding are a process of learning, changing, conveying and acting. The participants' enthusiasm of understanding the phenomenon demonstrated the authenticity in this study. This is also in line with S. Johnson and Rasulova (2016) who indicated that qualitative research affects the consciousness of the researcher and the research participants to the extent that it can change the way they understand the truth.

This fact allowed me to form the interpretations, taking into account the value-point of the participants, their voices, their diversity, their positioning and empowerment towards others and themselves. With this, both, myself as a researcher and the participants learnt to respect each other, to see the issues of the phenomenon from different viewpoints and subsequently negotiate the construction of truth.

I believe I was enabled to achieve the authenticity in this study due to the amount of time I spent in the field together with the participants. This also allowed me to develop effective relationships with them which facilitated the interaction, dialogue and observing them. This is detailed in Chapter Four.

3.8. Summary

This qualitative research design using phenomenology interpretative approach, explores the lived experiences of the nephrology nurses caring for the dying patients following the dialysis withdrawal. A convenience sampling method was used to invite eight registered nurses working in two private dialysis units. The information was collected by phenomenological conversation guides. The information was transcribed verbatim and analysed using Colaizzi's (1978) seven-step data analysis approach.

The following chapter (Chapter 4), presents the findings of this study.

Chapter Four

Description of themes

4.1. Introduction

This chapter presents the themes that emerged from the unravelling of the phenomenological conversations with the participants. My aim was to provide the reader with an understanding and insight into the participants' 'lived experiences of caring for dying patients following dialysis withdrawal. The participants' most poignant conversational narratives are illustrated in blue text to give a 'voice' to their lived experiences. Within the participant narratives, sound is indicated by [...] and gestures are indicated by {...}.

4.2. The Emergence of Themes

The information unravelled from the phenomenological conversations generated four main themes:

1. **Emotional trauma**
2. **Detachment**
3. **Loss of altruistic values in nursing**
4. ***being with death***

Table 7: Theme clusters, sub-themes and main themes

THEMES CLUSTERS	SUB-THEMES	MAIN THEMES
<ul style="list-style-type: none"> • Witnessing unrelieved patient's suffering) • Moral distress • Hopelessness • Insomnia • Fatigue • Difficulty concentrating and withdrawal from social engagement • Aches and pains and muscle tension • Scapegoat and finger pointing • Exclusion from decision-making • Self-expectation and reality. 	<p>Psycho-social effects</p> <p>Physiological effects</p> <p>Occupational stress effect</p>	Emotional trauma
<ul style="list-style-type: none"> • Personal detachment • Professional detachment • Letting go • Fear of being hurt • Avoidance 	<p>Nurse-patient detachment</p> <p>Nurse-family detachment</p>	Detachment
<ul style="list-style-type: none"> • Patient's finance • Manpower • Facilities • Constitution and patient's rights • Nurses' Scope of practice and patient's care 	<p>Resource constraints</p> <p>Compromised provision of patient care</p>	Loss of altruistic values in nursing
<ul style="list-style-type: none"> • Severing of umbilical cord • Emotional support needs • Unfinished business • Ontological confrontation 	<p>Watching and waiting</p> <p>Re-living the event of death</p>	<i>being with death</i>

4.2.1. Main Theme 1: Emotional Trauma

The care of the patient with ESKD dying after dialysis withdrawal was described by the participants as emotional trauma within three sub-themes.

1. **Psycho-social effects**
2. **Physiological effects**
3. **Occupational stress effect**

From the sub-themes, further theme clusters have been highlighted.

4.2.1.1. Psycho-social effects

Theme clusters:

- Witnessing unrelieved patient suffering
- Moral distress
- Hopelessness

Witnessing unrelieved patient's suffering

The participants were disheartened when they had to turn their patients away (send them home) due to institutional dialysis restrictions. The participants' feelings of an inward guilt of 'shame and blame' provoked significant emotions of being angry when their patients were discontinued from dialysis treatment.

Nicki explains:

'Being a nurse doesn't just mean being in a white uniform. I'm so ashamed to be called a nurse with health knowledge, but I can't help my patient.'

Beauty shares her story:

'As the unit manager, I get agitated with my staff when they ask me to do a favour and dialyze a patient with no funds or when patients who turn up to the dialysis center yet knowing that they are not eligible for dialysis.'

Queen expresses herself with an angry tone:

'How do you tell patients that you can't dialyze them, when you see them suffering?'... [Angry voice].

The interesting concept of emotional trauma was the fear, anger and self-blame, following the death of the patients after dialysis withdrawal. This corresponds with Kübler-Ross' explanation that when an important person dies 'grief, shame and guilty are not very far removed from feelings of anger and rage' (Kübler-Ross, 2009, p. 4). The participants expressed themselves with sentiments, associating them with the death of their patients in the following statements:

'To tell patients that they can't be dialyzed, is like throwing cold water on the person's face. It is like a death sentence.'... **Honey**

'I kept thinking about him, but I did not want to face him again.... I failed to save his life as a friend and a caregiver.'... **Zola**

'It feels like it is the nurses who are failing the patients.'... **Nicki**

Moral distress

The participants expressed their worry about the deaths of their patients, seeing that it could somehow be preventable.

'To say that you can't dialyze your patient while you have a machine and all the equipment, it is really a distress that I don't know how to explain it, there is no way to express that distress ... **James**

'You can't really do anything to save the life of your patient until the Doctor or Company decides for you what to do' ... **Zola**

'Being bound to policy and guidelines makes you sometimes feel that you are dehumanizing patients. How can you not help a patient who was on dialysis for so many years, and now watch him get worse and worse?'... **Beauty**

The inability to deliver patient care caused the participants to experience a sense of moral and emotional distress which was made worse when they watched their patients condition deteriorate, culminating in death.

Nicki stated, *'No dialysis, no life for patient with ESKD, seeing the health deteriorating, you can see that the person is dying so I just started seeing death on him.'*

'After dialysis withdrawal, the whole process is sad and painful. Watching your patient's condition deteriorating while you can't do anything is excruciating to experience.'[pause], [broke into tears] ... **Queen**

Hopelessness

Hopelessness is a feeling or state of despair or lack of hope (Miller, 2010). In this context, the participants exemplified their emotions of hopelessness when their patients were withdrawn from dialysis.

'I don't see any hope of the health system getting better. Our patients will always fall in the same pit. Unless the government changes the admission criteria, dialysis is expensive.'...

Beauty

'No hope of getting this system right, a patient with no dialysis access should be top priority for kidney transplantation, no matter what.'... **Jane**

'After her husband left, there was no hope to get her back on dialysis, all I could think of, was how I have failed.'... **Queen**

The 'hopelessness' concept created anxiety in the participants which led them to experience the emotional trauma after their patient's death.

'The access was getting worse every day and we could see where we were heading, the death was clear, there was no hope to recover.'... **Honey**

'It was obvious that after dialysis withdrawal, I could only think of the death. I could not give any hope of recovery to the family who were around their patient.'... **Milani**

'You are hopeless because you know your patient is going to die and you have no means to continue dialysis.'... **James**

The theme clusters of witnessing patient's unrelieved suffering, moral distress and hopelessness induced a tearful response from Queen. When asked a question of what she disliked while caring for the patient with ESKD dying after dialysis withdrawal, Queen reflected on the process of death and mentioned symptoms of death i.e. the swelling and shortness of breath and the hopelessness of being unable to relieve that suffering. While talking about that experience, she had an outburst of tears. The phenomenology conversation was suspended to allow her to recuperate.

Queen's narratives capture her emotional trauma which still lives inside her memory.

Personal Journal Entry 24/08/2017

The third phenomenological conversation was with Queen. My feelings after engaging with her, made me very apprehensive to continue further. In a way, I was also experiencing my own emotional trauma as I had had similar experiences with patients who were dying after dialysis withdrawal.

I felt anxious about my next phenomenological conversation and had even considered changing the topic of my study. The reality of being a novice researcher highlighted my lack of preparation for this type of research methodology. I felt the need to have a more personal conversation with my supervisor, rather than that of a student progress follow up.

My supervisor emphasized the importance of my personal and emotional investment that is required for a phenomenological study. Following our 'collegial' sharing of both our phenomenological journeys, I felt motivated to continue.

4.2.1.2. Physiological Effects

Theme clusters:

- Insomnia
- Fatigue
- Difficulty concentrating and withdrawal from social engagement
- Aches and pains and muscle tension

During the time caring for their patient up to the point of death, the participants experienced the physiological symptoms as discussed below:

Insomnia

All the participants verbalized that during their sleep they had a recurring image of their patients suffering, while they were dying. This caused the participants to struggle in getting to sleep and resulted in them waking up during the night.

'I constantly reflect about the reactions that the patients had after breaking the news that nothing else could be done to get the dialysis access. One patient's response was:" but sister I don't want to die." {Wipe off tears} I don't sleep soundly and sometimes get up and go into my lounge and cry.'... Honey

'Thinking about that friend (my patient) who was with me for so many years and passed away because of lack of money, I thought about it for a very long time.'... Queen

'You keep on thinking what to do in this case, and you find yourself dreaming and having sleepless nights.'... Zola

The study participants who experienced insomnia as previously mentioned, also had similar experiences of replaying the images of their patients dying even at rest. This was interpreted as an ongoing form of emotional trauma.

'I am a kind of a person who over thinks; thinking of what could have been done better. It takes me a long time to close my eyes at the night and I have to wake up early in the morning again to start the same cycle. That's really tiring. The patient and family look at you as a manager to assist and give them a positive answer, but I have nothing to say.'... Beauty

Fatigue

The theme cluster of fatigue was a common physiological symptom of emotional trauma.

'The ups and downs during the day, sorting out medical aid and finance problems and attending to the family members, is hectic' {bangs her hand on the table}. ... Beauty

'Dealing with the dying process and not sleeping well due to those unpleasant feelings, it is tiring.' ... Honey

Another symptom of fatigue was the participants close contact with their patients and not being able to alleviate their pain, causing them to be emotionally depleted.

[Expresses herself emphatically]. *'Death is painful, it is sore inside. Death is not something that will make you laugh; it makes you unhappy and creates unpleasant feelings such as anger and distress.'* ... **Honey**

'Definitely. I felt general tiredness; my feet and legs were very sore. I take a hot bath to relax my body and legs and soak my feet in salt water and some massage oil to relax my muscles.' ... **Jane**

'Being in that state of mourning and you have to be at work next day, for another twelve hours, sometimes you feel it is not fair on your body and your soul.' ... **Milani**

Difficulty in concentrating and withdrawal from social engagement

The participants constantly thought about the suffering of their patients and often this impeded their concentration in their nursing work.

'You are forever consumed by thoughts; do I continue with this relationship? What could I have done better? It is emotionally draining, it provokes your thoughts. I can't concentrate on my work.' ... **James**

'As unit manager, every time there is a patient taken off from dialysis; I keep on thinking about the patient's suffering and I can't catch up with my administration work. The thought never subsides.' ... **Honey**

'You can't focus on your work when you see someone outside the unit suffering and being short of breath and swollen, begging for dialysis.' ... **Zola**

The inability of the participants not being able to concentrate on the delivery of nursing care was a very stressful and anxious event. Within this context, this was viewed as a form of emotional trauma.

'It is stressful to be in front of patient and family who was with you for more than five years; telling them that you are not going to dialyze them. They think that you are the one who refuses to dialyze them.' ... **Nicki**

'I sometimes remember the hymn we used to sing with Michael (not real name) and out of my sub-conscience starts singing it. Other patients rebuke me; saying they don't want to die. This takes me back to my mourning moment, and I excuse myself to the bathroom to wipe away my tears.' ... **Milani**

Aches, pains and muscle tension

Aches and pains and muscle tension was found to be a common symptom with all the participants. The participants felt unwell and used different remedies to relieve their symptoms.

'You feel like you don't have legs; you try to take some painkillers, but it doesn't really help. My husband helped me, rubbing my shoulders with massage oil, that helped a lot.' {Smile} ... **Milani**

'I sometimes don't feel my body; it's like I have cramps all over my body. I take some pain tablets, but it doesn't really work because I have to wake up early in the morning again and be on duty for another day.' ... **Beauty**

'I could not wait to get home and put my feet in the salt water. My neck and back and legs were painful.' ... **Queen**

The participants, experienced chronic pain which they described as a pain that is 'inside or a mind's pain.'

'Every month-end I go for a therapeutic massage session for my back and neck. That gives me a bit relief, but the big thing is in the mind.' ... **Beauty**

'It is really sore inside, but I just cry inside.' [deep breath] ... **Queen**

'I take alcohol but socially to relax; just to relax and unwind. When the heart is pained because of sadness, nobody can pinpoint where that pain is. It is an emotional pain, it is in the head you just try to relax your mind' [nervous laugh]. ... **James**

4.2.1.3. Occupational stress effects

Occupational stress is viewed as a discrepancy between environmental demands and the employee's capacities to fulfil those demands (Vermunt & Steensma, 2005).

Theme clusters:

- Scapegoat and finger pointing
- Exclusion from decision-making
- Self- expectations and the reality

Scapegoat and finger pointing

All participants expressed that they felt like a victim, especially when the patients' medical funds were depleted and/or when dialysis access was no longer possible.

'The nurse is in middle of everything, you are the last resort, the doctors do their things and send the patient to you, and the patient and family's eyes are on you. This makes you feel like a victim.' ... **Jane**

'You are a victim of all this mess. Patient and family see you as a careless person as they think you are ignoring them because they don't have money anymore.' ... **Zola**

'When the patient is withdrawn from dialysis you are really a victim because you have to suffer the feelings and the emotions attached to the dying process afterwards.' ... **James**

The experience of 'finger pointing' was very apparent for the participants.

'There is an expectation that you must dialyze the patient and the expectation from the doctor and the expectation from the company, you are in the middle of all of them. They all look at you.' ... **James**

'You are the last person to be there. Doctors failed, system failed, and all come back to you. Whatever went wrong either from patient's side or from treating team side, you have to bear it all.' ... **Milani**

'Once the dialysis is withdrawn due to access failure, the patient is sent to the nurses, and doctor give you the order to continue as much as you can. So, the family and the patient come

to you saying, "Doctor said" ... you find yourself in the middle of the big sea {Raising eyebrows}." The patient and family see you as the one who doesn't know what to do.' ... Honey

Exclusion from decision-making

According to the participants, the patients are admitted by the doctor and the treatment contract is made between the patient and the dialysis provider company. For this reason, the participants felt that they were excluded in the patient's admission process as well as in the decision-making regarding dialysis withdrawal. This was interpreted as an equivalent to a 'third party' as the nephrology nurses were less involved in the matter of resources, admission and withdrawal of dialysis.

'It is all about what the doctor says and the company's policy. I only see the patient coming to dialysis; not involved in their decision-making. Nurses will just execute orders.' ... Nicki

'If I was contacted, with the experience that I have in dialysis, I would have advised not even starting dialysis, rather let the patient rest and die peacefully.' ... Honey

By not getting involved in decision-making matters, the participants voiced their feelings of having a sense of low self-esteem, frustration and job dissatisfaction. This was found to be a cause of their emotional trauma which increased, following the deaths of their patients.

'Feeling useless, feeling powerless, I became very despondent, I felt I served no purpose in her life [with sad voice]. Our friendship became meaningless. No support as a friend.' ... James

'You don't have a choice but to accept your weakness ... Once this patient is kicked out, you have a new patient coming in his place, so work goes on.' [sighs deeply], {lifts up his shoulders and faces the ceiling}. ... Zola

'Seeing that I was a health professional, but someone dies, doing nothing despite that special bond I had with her, I really felt I am nothing.' ... Queen

Self-expectations and the reality

The participants expressed that should they have been given an opportunity to deliver expert nursing care together with the available resources, perhaps their patients may have survived.

'The moment the medical-aid was stopped, the dialysis was cut off; that was a huge disappointment by the healthcare system as we couldn't really make a plan.' ... **Queen**

'The nephrology nurses do not create the access. I felt disappointed by the healthcare system as it couldn't make a plan for us to dialyze this patient or plan for a kidney transplant.' ... **Honey**

The participants were expected to deliver quality patientcare; however, they were unprepared to cope with their emotional needs after their patients were withdrawn from dialysis. This was a major source of personal stress.

'It is part of our job, we have to do our job {open arms wide, takes a deep breath}, but it is meaningless to see your patient getting sick and very sick. Your nursing knowledge is not used. There is little that you can do as a nurse.' ... **Honey**

*'Seeing that your patient can't really get dialysis and all eyes on you to do something, you ask yourself a lot of questions. Whether **you** {emphatic} can pay for your patient? - but for how long you can do that? Because you really don't want your patient to die while the treatment is there but also because of money.'* ... **Queen**

'She could have been transplanted but money was an issue {shake head, sad}. I wish I was a superhero to pay for her dialysis sessions.' ... **James**

4.2.2. Main Theme 2. Detachment

Having felt that they had failed their patients, the participants anticipated that death will follow shortly. It was at this stage that the participants began to detach themselves from the patients and their families. This was interpreted as a coping mechanism that the participants used to disconnect themselves emotionally and physically from their patients and their families. The participants also had to detach from the withdrawn patients and their families to be able to keep a work-life balance and continue to care for the other patients.

The experience of detachment evolved from the following sub-themes:

1. **Nurse-patient detachment**
2. **Nurse-family detachment**

4.2.2.1. Nurse -patient detachment

The nature of being a nephrology nurse and caring for patients (and their families) on dialysis creates relationships and bonds that are formed over many years. When this relationship is terminated, there is a profound sense of detachment. In the nurse-patient relationship detachment process, the following theme-clusters emerged:

- personal detachment
- professional detachment
- 'letting go'

Personal detachment

The participants referred to the patients as 'their own patients' or 'their own family members' or their friends.' It appeared for the participants that there was a sense of 'ownership.'

'I try to care for my patient as much as I can, I believe what I have given will be given back to me.' ... **Jane**

'It is not comfortable to tell someone who has been your friend that you can't dialysis him/her. I rather refer the person to someone else. You cannot explain how you cannot give to your patient what you have to save her life.' ... **James**

'I was in the bed the whole day at home when my patient passed away.' ... **Milani**

The participants predicted that when death was imminent and that these bonds between their patients and families were threatened, they sub-consciously began terminating these bonds.

'Knowing that there was no other means of treatment I knew the end was death and I just saw a better life in the "after-death" space where will be no need of dialysis.' ... **Nicki**

'I have been with her so many years, seeing her suffering, it is better she dies and no more up and down coming to dialysis in the early morning.' ... **Honey**

'I have been with her for eight years, I cared for her as my own mom, she has been dependent of dialysis for her whole life, but now that she died, she has no more pain, may her soul rest in peace.' [teary] ... **Queen**

Professional detachment

Within this theme cluster, the participants role as a nurse was transformed into what seemed a financial consultant which added to their frustration and sense of failure in not being able to deliver patient care.

'I had to deal with the company, negotiating for some free sessions for my patient and had to deal with medical aid, phoning and asking for a favour, trying to explain that the husband is busy sorting it out and pushing the husband to make payment.' ... **Queen**

'You know you have nowhere else to send this patient for further treatment. You have to make a plan, phoning around in the state hospital and ask if they can assist the patient for a while, while fixing the financial problem, but this is not always successful.' ... **Zola**

This sense of professional detachment was a difficult concept for the participants to experience. They all expressed professional detachment from their patients which negatively impacted on their lives. A consequence of this professional detachment was nephrology nurses leaving this nursing specialty to rather seek employment in a less stressful area of nursing.

'I am actually thinking of leaving this career to study something else. It is difficult to carry on this way, because it is not easy to get rid of your patient in your mind the moment you are still thinking about your patient whose dialysis was withdrawn, you get a new one to care in his place while waiting for that one to die.' ... **Zola**

'I spoke to many nurses who left renal wards and many of them said it was because of the patient's death. You get used to a person. Surprisingly in the morning when you come on duty, you hear the news, the person is gone, or collapsed on the machine.' ... **Milani**

I have decided to reduce the conversation time with patients to prevent that closeness. But because I was too much in the unit, relationships were created unintentionally. I decided to move to the acute section where I nursed a very sick patient and for most of the time not even able to talk to them. That was a relief for me.’ ... Jane

Letting go

The participants displayed their emotions of bond-breaking when they realized they have exhausted all their means to continue treatment. Loss was evident in their narratives by admitting that their patients were suffering, and it was a relief for them to die.

‘My patient suffered a lot, I have done what I could, and I put the patient now into God’s hands. May his soul rest in peace.’ ... Jane

‘He had a difficult relationship like me (divorced) and suffered from kidney failure. It was a good thing that he died rather than travelling up and down for dialysis.’ ... Beauty

‘My patient was dying. I wanted to pay for his dialysis, but I had no means. I just prayed for him to rest in peace where he will never suffer anymore.’ [sad voice] ... Nicki

4.2.2.2. Nurse-family detachment

Theme clusters

- Fear of being hurt
- Avoidance

Fear of being hurt

When the patient was withdrawn from dialysis, the participants observed the reactions of the patients and the families. All participants reported the patients and family members’ attitude change towards them.

‘The family was not happy with all the processes. And all were coming to me as I was the unit manager. It was like they wanted the money returned that they spent on dialysis before. The cousin said, ‘you guys, it is all about money, look at how much money we have spent but you can’t even help him from all that money we have paid.’ ... Beauty

'Family and patient think it is you who doesn't want to dialysis this patient, because it is you that they see, like you are not caring for their family member who is suffering.' ... **Nicki**

'You don't know what this family is thinking. The family was paying for so many years and they paid a lot of money but suddenly they stop dialyzing him because now they couldn't pay. The family members were angry, they don't understand that they were not paying you.' ... **Zola**

Avoidance

The reactions of anguish and frustration from patients and their family members made the nurses to feel helpless and vulnerable and they experienced the fear of being hurt by them. This was apparent in their narratives, they feared to face them again, after their patient passed on.

'I was lucky I moved from that unit. After her death, I thought this man will come back to the unit to look for me because I was angry with him and it was like harassing him for him to pay for his wife's dialysis.' ... **Queen**

'I was afraid of his family, what to tell them. That's why I didn't want to go to visit him. His family is also from my side, so to them is like, it is me who didn't care for their family member (the patient).' ... **Milani**

'He looked at me like I was the one who did not do my work properly, especially when the machine was alarming due to poor flow, that made me afraid to face him after the death of his dad.' ... **Jane**

The participants found it very difficult to face the patients and their family members after dialysis withdrawal as they felt worthless and disloyal in front of their patients' family.

'The family knew me being closer to her, she used to introduce me to them as her nurse and a friend, so it was not easy to face them after her treatment was withdrawn.'... **James**

'Family knows exactly that patient shouldn't come to dialysis when the medical aid is outstanding, but they still come and ask you those questions that you don't even know how to answer, because as nurse you don't deal with finance.' ... **Milani**

'I always dialyze him during the morning hours, before his son comes, who expected me to be a miracle worker, asking me questions and I rather referred him to the doctor.' ... **Jane**

The avoidance was a tough moment for the participants as they had to find a way to detach themselves from the family and terminate that existing nurse-family relationship.

'I stopped talking with the patient and the family as I couldn't give them that reassurance, I didn't want to face them, because I felt a failure already.' ... **Beauty**

'When I saw him coming, I rather asked someone else to attend to him. You don't want to get into an argument with the family, you keep yourself busy.' ... **Nicki**

'When the dialysis stopped, I avoided this patient because I knew that if I contacted him or his family, they will think I am giving them a hope that I can do something.'... **Zola**

4.2.3. Main Theme 3. Loss of Altruistic Values in Nursing

Fahrenwald et al. (2005), proposed that nurses require five core values to care and practice their profession. A nurse must be able to demonstrate; (i) human dignity; (ii) integrity; autonomy; (iv) altruism and (v) social justice. Within these core values, the theme emerged from the phenomenological conversations was the 'loss of altruistic values in nursing.' Altruism is seen as taking care of the welfare and well-being of others (Fahrenwald et al., 2005). The participants narratives revealed that they felt hindered in practicing the altruistic value of nursing. The following sub-themes capture the participants altruistic challenges:

- 1. Resource constraints**
- 2. Compromised provision of patientcare**

4.2.3.1. Resource constraints

Within the sub-theme of resource constraints, theme clusters were identified:

- patient finances
- human resources
- facilities

Patient finances

The participants highlighted the issue of financial viability as the main concern that hindered the delivery of patientcare in the dialysis settings. It was felt that this obstacle interfered with the value of nursing.

'All is on the agreement that the patient signs, but nobody predicts the circumstances. Many patients are dependents on their relatives who can change their minds or also face financial difficulties, resulting in the medical aid being suspended for these patients.' ... **Nicki**

'The finance is the main issue in the private sector as obviously it is about a business. That is an agreement between patient/family and the company. If there is no money, no treatment.' ... **James**

'A patient has to sign a treatment contract. Once there is no payment, it is seen as a breach of the contract and the treatment stops.' ... **Zola**

The participants were heartbroken when they had to send their patient back home knowing that without dialysis they will die. In the phenomenological conversations, their narratives revealed their emotions of altruisms and empathy towards their patients. However, they felt overwhelmed by their powerlessness to practice altruistic values of nursing. I interpreted this scenario as one of an 'executioner' rather than that of a 'protector.'

'You don't have a choice but to accept your weakness. Once this patient is kicked out, you have a new patient coming in his place, so work goes on.' ... [sighs deeply], {lifts up his shoulders and faces the ceiling}. **Zola**

'They know (patient/family) they have failed their treatment contract agreement with the company. This is seen as a breach of contract and consequently the treatment stopped.' ... **Nicki**

Manpower (Human resources)

The shortage of nursing staff was highlighted by the participants as another resource constraint when caring for the patients with ESKD on dialysis.

'Shortage of staff in the renal nursing profession is a concern. You can't even grieve for your lost patient because there is no staff to replace you.'... Queen

'I was at home in the bed the whole day when my patient passed away. I felt very weak, but I had to come to work the next morning as there was no one to work in my place. There are no agency nephrology nurses to cover our staff shortages' ... Milani

In professional practice, altruism reflects not only the welfare of patients, but also of other nurses and healthcare providers (Fahrenwald et al., 2005). The participants felt left out when they lost their patients due to insufficient staff. They could not get enough time to grieve for their loved ones as there were no personal staff to cover their shifts.

'After the death of your patient, unfortunately you have to carry on with the work as there are not enough staff to cover the shift. You only have a short debriefing in the tea room and come back on the floor.' ... Honey

'You can't have a day off when you lose your patient, you have to come to work and carry on. Not even a time to attend funeral unless you are lucky to be off that day.' ... Zola

'You just grieve inside and carry on caring for other patients.' ... James

Facilities

When a patient is receiving treatment in the private sector, it means that the patient is able to cover the costs incurred. When the patient becomes unable to cover the cost, he/she is referred to the state hospital where they will be treated according to the available resources (Moosa, 2010). In terms of dialysis, the healthcare facility must be equipped with specialized dialysis practitioner staff, the dialysis equipment and enough water supply with adequate pressures to create the special dialysis solution to clean the blood during each dialysis session. This makes a dialysis healthcare facility very expensive.

In the Cape metropole area where the participants practice, there are only two provincial hospitals which are equipped with dialysis facilities. However, patients who do not meet the Western Cape Provincial Health Admission Criteria (Table 2, page 4) are denied access to

these healthcare facilities. This challenge could also be likened to emotional trauma, as the participants could only send these patients home to die.

'You deal with patients like this until death, there is no available clinic or dialysis centre for the patients with kidney failure withdrawn from dialysis.' ... **Beauty**

'There are no facilities for post-dialysis withdrawal care like palliative care for the patients withdrawn from dialysis. All comes back to us and we are not trained regarding palliative care.' ... **Zola**

'Nephrology nurses are not trained as palliative care nurses, but we have to care for the patients who are dying after dialysis withdrawal, because there isn't any facility to send them.'
... **Queen**

The lack of means to treat the patients hindered the nephrology nurses to offer their altruistic values to the patients. From the participants narratives, they claimed that the beds (spaces) became competitive due to the long waiting list for dialysis. As soon as a patient is withdrawn from dialysis, or dies, a new patient is admitted. The participants indicated that when their patients were brought into the unit in a critical condition after dialysis withdrawal, it was often difficult to access a ward bed to provide basic nursing care.

'Your patient, sitting in front of you in a wheelchair and is short of breath, swollen legs and face and you can't do anything. No space for him, you just get busy with a new patient in his bed.' ... **Zola**

'To see a patient suffering and begging you for dialysis, and you know if the person is dialysed will be better, but you can't help him. First of all the person is not counted anymore and is not booked for the day, so there is no bed for him.' ... **Queen**

'You get patients phoning you asking you if they can come in the place of someone else who is absent. The person is worried about his life, but there is no place unfortunately and you cannot swop the names.' ... **Honey**

4.2.3.2. Compromised provision of patientcare

Patientcare provision was of a concern expressed by all the participants. As the patients were being withdrawn from dialysis, the participants experienced difficulties in rendering nursing care to these patients. The following theme clusters were generated from their narratives:

- The Constitution of the Republic of South Africa and Patient's Rights.
- Nurses 'Scope of practice and patientcare

The Constitution of the Republic of South Africa and Patient's Rights

The participants were aware that the Constitution of South Africa has a Bill of Rights (The Constitution of the Republic of South Africa,1996), which stipulates that all citizens have a right to healthcare. When their patients were denied the access to dialysis, they felt a great sense of disappointment and failure as a caring health professional.

'In the patient's rights include palliative care but our patients don't get access to these rights, so there is nowhere to refer them after dialysis withdrawal.' ... **James**

'As set out by the constitutional right for patientcare, my patient was young in his forties', his right to be cared for was violated. I feel that not all means were made available for his treatment.' ... **Beauty**

'The constitution of the country has set the bill of rights and they say that every person is entitled to quality health care. So when I see the patient with kidney failure turned away because of the funds, I really see that the patient's right to health was not respected.' ... **Milani**

To alleviate some of the pain caused by generalized oedema and shortness of breath, dialysis is the only option to remove fluids and body waste which become toxins. The participants were saddened by watching their patients 'condition deteriorate due to toxins and were helpless to provide even basic palliative nursing care. The participants viewed this as a loss of the meaning and value of their caring profession as a nurse.

'The system we work in is uncontrollable and fails us to render our professional oath to the patients, we fail our nursing profession.' ... **Zola**

'You can't exercise the nursing fundamental roles to alleviate suffering and comfort your patient by removing fluids and toxins, you are actually useless, you don't deserve to be called a nurse.' ... **Nicki**

Nurses' Scope of Practice and patientcare

The main role of a registered nurse is to carry out his/her duty to a patient by ensuring the improved service to patient. Within their scope of practice, nurses have a right to practice in a safe working environment which is compatible with efficient patient care and which is equipped with at least the minimum physical, material and personnel requirements (South African Nursing Council, 2004-2018a).

Within these regulations that govern nursing practice when dialysis is withdrawn, the participants are legally bound to render patient care (South African Nursing Council, 2013). However, within some private renal care facilities, nephrology nurses are accountable to adhere to policies which often minimize patient care after dialysis withdrawal. The participants expressed that their patient care role was compromised by these policies.

'You take the oath to help people but, in this case, you are bound by certain criteria of the company's policy and guidelines and rules, you can't practice it, you really feel disappointed' {scratching her head}.' ... Beauty

'As nurses, we pledge to care for the patient, but the company policy and procedures make the care chaos, because they interfere with this pledge. The nephrology nurses care for the patient, the family and the company.' ... Zola

'When a patient is withdrawn from dialysis you still have that patient's care within your scope of practice, but in the private you have to abide to the policy and guidelines of the company which determine how far you can go within your scope of practice.' ... Nicki

To protect themselves from any non-adherence to the institutional policies, the participants felt compelled to work within these policies and protocols. Their narratives revealed that they developed a resistance to this environment by keeping themselves busy which resulted in less contact with the patients and their families. Further to this, the participants felt that they had also cut back on the nursing care of their patients. This was viewed as a "loss of nursing altruistic values."

'I feel I am too much with the machine than with the patient. To prevent too much talk with patients, I focus more on the machine than on the patients.' ... **Nicki**

'When the patient starts talking about something that is not dialysis related, I don't feel like going talking anymore and I excuse myself to do something else.' ... **Zola**.

'More you talk, the chance you overstep the border line. I only speak to the patient about the dialysis treatment stuff, but I miss that conversation with my patients.' ... **Milani**

4.2.4. Main Theme 4. *being-with-death*

The participants explained that their patients with ESKD are dependent on dialysis with the view that they may never regain normal kidney function. When dialysis is withdrawn, the patients are most likely to die but the time is not predictable. In these instances, the participants are still able to converse with the patients and be present during the dying phase.

The sub-themes below informed the main theme of *being-with-death*.

- 1. Watching and waiting**
- 2. Re-living the event of death**

4.2.4.1. Watching and waiting

Despite the withdrawal of dialysis intervention, the patients together with their families are opportunistic in that they will still come to the dialysis unit in hope that they may receive even a once off dialysis session. Attending the dialysis unit, became a routine and the patients continued to go despite their poor prognosis. The participants described this phenomenon as one of the protective measures, especially for the patients' families who were distressed in watching their loved one dying. The participants were a 'sounding board' and as a confidant for both the patient and family (Brokalaki et al., 2001). However, for the participants in this study, it appeared that their presence and exposure to dying and death(s) of their patients was more pronounced than in other disciplines of acute care nursing such as intensive care, cardiology and trauma. In this sub-theme of watching and waiting, two theme clusters were identified.

- severing of the life-line
- emotional support needs

Severing of the life-line

The treatment modality of dialysis is a life-line for patients with ESKD. It can be extrapolated that when dialysis is withdrawn, this life-line is severed. I interpreted this as a 'severing of the patient's umbilical cord'. My thinking was in-line with a new born baby and the cutting of the umbilical cord (venous access and dialysis catheters) from the mother (renal replacement therapy) who had brought life to her baby. However, in normal circumstances, the baby should survive. In this instance, the severing of the umbilical life-line resulted in the patients dying and eventual death. Awareness of dying and death after dialysis withdrawal was expressed by the participants in their narratives as follows:

'When dialysis stopped, seeing the patients' conditions deteriorating, you can see that the person is dying so I just started seeing death on him {Closing her eyes}, [deep breath].' ... **Nicki**

'Because dialysis was withdrawn, I switched off my mind about not being with him anymore as I noticed the death coming. I just said goodbye inside me.' ... **Beauty**

'After disconnecting him his last session, I pressed his fistula to stop bleeding and that allowed me to be too close to him and inside me I said goodbye to him, because I knew once dialysis is withdrawn the next phase is death {Wiping tears}.' ... **Milani**

The eventuality of impending death was an overwhelming situation for the participants.

Honey explains:

'Seeing that there was nothing else that could be done, I started giving up in mind but not in my actions. I continued caring for the patient until the end of his life. The patient was sent to trauma unit and passed on [With a sad voice].'

My patient went through a lot, but he was getting better on the machine. His cousin kept bringing him in the unit after dialysis withdrawal to try his luck. It was sad that I could not do more to continue with his treatment. Just watching him dying and send him back home. Few days later the family phoned to tell us that he passed away [Teary and taking a deep breath].'
... **Beauty**

Emotional support needs

The participants had emphasised the need for support after the death of their patients. They all claimed to be human beings who cared about other human beings and had formed relationships with each other. The deaths of their patients required emotional support for them to accept and cope with loss.

'We are not working with dogs. We develop relationships with our patients and when they die, we also get emotionally affected. We also need support. Here you have to grieve on your own time {Banging the table with his hand}.' ... Zola

'Nurses are also human beings with emotions and families. You are sad when you lose a patient and you need to deal with those emotions. You need support.' ... Queen

'When your patient dies, you mourn on your own. Sometimes we have a short informal debriefing session among staff - but you really don't get rid of those emotions.' ... Nicki

The participants were offered support (ICAS) from the healthcare facility, but they felt that this service was inefficient, as most of the time the service was provided over the telephone and was very brief. The participants also claimed that most of the time ICAS would call them whilst they were on duty. This was not satisfactory or helpful as the participants needed to return to caring for their patients.

Beauty says:

'I seek support from my pastor and talk to ICAS when I feel that it is becoming unbearable. But, ICAS is mostly over the phone unless the case is severe, and all staff are affected. Then they will send someone to the unit.'

Milani shares:

'There is no available effective emotional support that you get at work. The company provides the staff ICAS, with whom you have to speak over the phone for a few minutes as you have to go back to work. I only get support from my family.'

James expresses himself:

'The company provides ICAS for the staff who indicate the need for counselling. Personally, it is not adequate. ICAS is mostly counselling over the phone. It is a stranger. Rather seeing the person physically, it adds value. You feel more valued and cared for.'

4.2.4.2. Re-living the death event

The participants often are excluded from normal 'after death' rituals such as the funeral or memorial service. This may be an opportunity to say goodbye to their patients with whom they have developed a bond. Not being able to say goodbye may be viewed as 'disenfranchised grief', in which their grief is not recognized, thus leaving them with limited opportunities to grieve (Doka, 2002). Their experiences of 'disenfranchised grief' may be as a result of the participants not being available to attend the funeral(s) or memorial service(s). The other reason was the unwillingness to reconnect after having terminated the bond with patients and their families at the time of death. In addition, participants were not present at the time of death and were denied the opportunity to say 'goodbye' which was seen as prolonged grief period.

In this sub-theme, two theme-clusters emerged:

- Unfinished business
- Ontological confrontation of self and death

Unfinished business

The participants raised a concern that when their patients were withdrawn from dialysis, they were not given a chance whilst on-duty to check on their patients at home. The participants mentioned that even though their patients were not suitable for access to private medical services, there remained some important needs regarding nursing care and support for the patients' families during the dying phase. They felt that they should be allowed to help with basic nursing care and family support, including what to expect as death takes place. This omission of patient and family involvement at dying and death was deemed as 'unfinished business.'

'The suffering of Mrs S is still living in me. I had a journey with her for nine years on dialysis. When withdrawn from dialysis, due to lack of funds, I had no opportunity to go to visit her at home and spend her dying time with her. When she passed on her family informed me, but I was unable to attend her funeral to pay her last honour {Face down}.' ... Queen

'When your patient is withdrawn from dialysis and dies, you are not next to the bed. You hear the family informing you that he died. No chance to say goodbye to that person, and you don't have time for sharing the sadness with the family as you fear to face them.' ... **Nicki**

The participants expressed their emotions of re-living the loss of their patients during anniversaries and certain holidays, or when the topic of death or other losses were discussed. These situations appeared as a form of unprocessed grief and unfinished business of letting go and saying goodbye.

'Sometimes this patient pops up in your mind and you realize that this person is no more with you. You reflect about it and just carry on with your work. Like the way he used to preach to us the word of God in the morning. We miss that. No one is doing that in the unit. We all still talking about him.' {Facing the ceiling and raising her arms and shaking her shoulders} ... **Nicki**

'I sometimes remember the hymn we used to sing with him and subconsciously I start singing it. Other patients scold me, saying they don't want to die. This takes me back to my mourning moment [With a sad voice].' ... **Milani**

'I used to watch cricket with him, and even today when I am at work and cricket is on TV, I remember him and realize that he is not here anymore.' ... **Jane**

The fear of death was marked by the participants in the phenomenological conversations by their views of what death is and how death consumes them.

'Death lives in us, when I see patients suffering, I just pray for them to die peacefully {Bending her neck, with eye contact avoidance}. ... **Milani**

Ontological confrontation of self

Ontological confrontation is the precise and immediate knowledge of individual mortality which can arise whenever a person's regular defences toward death awareness are intruded upon by situations or surfacing memories (Nugent, 2013). All of the participants claimed to know that they will die but emphasized that they did not want to die from ESKD.

'Patients are afraid of skipping dialysis because they fear they're going to die. Same as myself, when I see the way they suffer, I am afraid I will go the same way [Raises her voice]. *The death of the patient with ESKD makes you pray that you do not die with ESKD. It is unbearable. It makes you think about the death of other patients and of yourself.'* ... **Beauty**

'I know I will die but I pray not with a kidney failure. Is not good. It is painful disease.' ... **Nicki**
Being exposed to the suffering of the patients with ESKD, the participants became scared of death especially if they should develop kidney disease. Their conversations revealed that they were taking some precautions regarding kidney health.

'Yes, I fear dying with kidney disease that's why I now drink a lot of water to prevent this disease, I don't want to die with kidney failure {Shaking head}.' ... **Beauty**

'Death is like a thief. Nobody can keep death away. It will happen to anybody, but kidney failure is the worst disease. I don't want to die with it [raised voice, no, no, no, no]. I try to prevent it as much as I can like doing exercise and eating healthy.' ... **Milani**

'I even think of myself when I am paying medical aid, I think of how I will be treated if I get sick with this disease.' ... **James**

Even though there was an indication that death is part of life, the participants still had a fear of the unknown after death.

'I think about how my own death will look like. Of course, I fear death because I don't know what happens in the afterlife {Opening her eyes wide, staring on me}.' ... **Jane**

'Death is scary. You can't get used to death, because it gets even worse when you see people dying. You start questioning yourself who is next? Including yourself {Looks worried}.' ... **Zola**

'Death is horrible. You don't know what to expect on the other side [Opens both hands on the table].' ... **James.**

The participants' conversations disclosed that no one wants to die, however they would prefer to die from old age.

'Everyone will die, but I would like to die peacefully. Not now though, when I am old. I just sleep and die in my bed {Smiles}.' ... **Queen**

'I don't want to die now. I am still too young, and my children still need me. I have no choice that I will die but only when I am old, and my children are grown up, then I can die' {Closes eyes, pauses}. ... **James**

4.2.5. Summary of Findings

In this study, the findings really surprised me. I found that the care delivered to the patients was far more than a simple act of basic care. The participants were not only care givers, but also friends as a result of long-term treatment contact. After dialysis withdrawal, the participants had to find a way to detach themselves from an existing bond that had developed over time. This detachment process was not easy for the participants and consequently caused physical and psychological symptoms such as anxiety, aches etc.

To deal with the emotional experiences associated with the loss of their patients who have become significant others to them, the participants adopted avoidance behaviour as a coping mechanism. This resulted in reducing the quality of patient's care delivery to other patients assigned to them. This also had a negative impact on some of the participants, as they felt they would rather resign and seek for a job into less stressful nursing disciplines.

The participants own expectations was to care for their patients until they died but became entangled between professional ethics and institutional policies. This entanglement caused a sense of disappointment and a sense that the nursing profession had lost its mandate of patientcare. This was also identified as a knowledge gap in caring for the dying and preparing for the deaths of patients following withdrawal of dialysis.

In addition, the fact that the participants did not have a chance to pay last respects to their patients, there was a sense of 'unfinished business.' The participants were often unable to be with their patients when they died and furthermore could not attend the funeral. The participants felt that they had not completed the journey with their patients by being with them in the last phase of their life cycle. This unfinished business caused the participants to have a sense of everlasting grief.

Furthermore, watching the patients suffering caused the participants to become afraid of facing their own ontological issues with death.

In Chapter Five, I will elaborate on the four themes that emerged from the participants narratives and discuss further their experiences of caring for the dying patients with ESKD after dialysis withdrawal. I will discuss and relate the findings to the literature reviewed for this study.

Chapter Five

Discussion and conclusion

5.0. Introduction

The aim of this study sets out to better understand nephrology nurses' lived experiences of dying and deaths of patients with ESKD following withdrawal of dialysis. To achieve this aim, the following objectives were set out:

- To explore and describe nephrology nurses' experiences and emotions of caring for dying and coping with deaths of patients with ESKD following dialysis withdrawal.
- To identify the knowledge gap in them caring for the dying and preparing for the deaths of patients following withdrawal of dialysis and,
- To determine the emotional and educational needs of these nephrology nurses and offer teaching and learning recommendations for this group of nurses.

5.1. Discussion

The study highlights the challenges that nursing participants faced whilst caring for dying patients after dialysis withdrawal. From the phenomenological conversations, four themes emerged and will be discussed in relation to the reviewed literature.

5.1.1. Main Theme 1. Emotional Trauma

Psychological or emotional trauma is damage or injury to the psyche after living through an extremely frightening or distressing event and may result in challenges in cognitive and physical functioning or impede coping normally after the event. The emotional trauma experienced by the participants while caring for their dying patients consisted of three aspects: (i) psycho-social; (ii) physiological and occupational stress effects (Polit & Beck, 2017).

Psycho-Social Effects of Emotional Trauma.

Psychosocial health encompasses the mental, emotional, social, and spiritual dimensions of what it means to be healthy (Zinger, 2011). Based on Zinger's (2011) definition of psychosocial health, the participants in my study, demonstrated unnatural behaviour especially emotionally and mentally. These unhealthy factors will be discussed in each theme clusters emerged from the sub-theme of Psycho-Social Effects of Emotional Trauma. The theme clusters are the following: (i) witnessing unrelieved patient's suffering and (ii) moral distress and hopelessness.

Witnessing the unrelieved patient's suffering

For many years suffering along with physical pain and illness has been acknowledged in the literature (Cassell, 1991; Gadow, 1991; Rodgers & Cowles, 1997). One definition of suffering is viewed as bearing or experiencing pain, distress or injury (Webster's New World College Dictionary, 2010). Cassell's (1998, p.640) concepts of physical pain and suffering have three comprehensive differences:

1. The first point of Cassell's suffering description is that 'suffering is experienced by persons as a whole; not only in body, mind and spirit.'
2. Secondly, suffering occurs when an 'impending destruction' is perceived by the person; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner.'
3. Thirdly, suffering can be defined as the 'state of severe distress associated with events that threaten the intactness of the person.'

More recently, suffering has been defined as 'something that calls for restoration to make whole that which is broken' (Rattner & Berzoff, 2016, p. 241). The authors also agreed with Cassell (1998), that in the case of dying, the 'threat of disintegration continues, and the reality of suffering cannot be fixed' (Rattner & Berzoff, 2016, p. 241). Furthermore, the authors

agreed that unrelieved suffering does not only affect the patient, but also the family and others who care and become part of the suffering process.

Rattner and Berzoff (2016) described that healthcare professionals feel a sense of failure, helplessness, sadness, and a feeling of being overwhelmed when faced with the unrelieved suffering of patients and families. This feeling of failure was expressed by nurses who were in direct contact with patients and their families and experienced a disappointment in their inability to relieve such suffering (Ferrell & Coyle, 2008).

During the phenomenological conversation with the nephrology nurses, the exposure and impact of not being able to relieve their patients' suffering was very evident. This caused the nurses to become angry, ashamed and guilty. These emotions of unrelieved patients' suffering were the most provoking aspect of emotional trauma expressed by the participants.

James shared his experience:

'{Sighs deeply} ... The whole process is painful. It is a heart breaking. It is stressful to tell your patient that you can't dialyze him. The family knows you and they bring the patient suffering from shortness of breath and swollen to the unit, and you say that you can't dialyze your patient, it is really a distress that I don't know how to explain it {head down}, there is no way to express that distress. You feel guilty about your patient's suffering.'

The nurses were disheartened when they had to turn away their patients who were suffering from pain, shortness of breath and generalised oedema without dialysis on account of departmental restrictions. The feelings of an inward guilt and shame provoked significant emotions of anger when their patients were discontinued from dialysis.

Zola's sentiment:

'Your patient sitting in front of you with shortness of breath and swollen legs and you can't do anything? You are useless. You are the one who disappointed the patient, not the company. This hits on your nerves.'

In the phenomenological conversations, the participants referred to the suffering when they spoke about their patients and related their suffering as 'pain' or 'painful' or 'sore.' This correlates to the findings of other authors (Cassell (1991), Gadow (1991) and Rodgers and Cowles (1997) who used suffering in conjunction with pain.

For example, **Milani** says:

'To see your patient suffering, is painful and heart breaking {pause, deep breath}. When my patient died, I felt very bad, I was not sick, but all my body was sore, and I could not explain my feelings, I was just numb.'

The witnessing of the unrelieved suffering of their patients evoked anger, shame and guilt for the nephrology nurses mainly because of the intense bond that had developed over time whilst the patients were receiving dialysis. The nurses 'experience of anger, shame and guilt was caused by the fact that their patients 'life-world' value had not been considered. Their sentiments are in line with the definition of this concept of 'life-world' by Merleau-Ponty (1996) as 'our being in the world' or the way we experience our *everyday life*. These nurses regarded their patients also as friends to whom this patients' life-world was disclosed and entrusted. The withdrawal of dialysis was viewed as failing their friends which caused an internal feeling of guilt and shame.

James describes his experiences:

'It is an embarrassment and a shame. You have somebody that you are laughing and joking with, but suddenly you are shy to speak with the person because of the things that you cannot control' (healthcare provider's policies and procedures).

The experience of being left alone with no support from the healthcare system made these nephrology nurses also angry. This anger was further aggravated as these nurses were not part of the decision-making process regarding dialysis withdrawal. The nurses were following the order(s) from the medical practitioner and the healthcare provider. Witnessing this suffering and being unable to alleviate it, caused further emotional turmoil. These nurses also expressed that they were not honouring their professional oath to provide care and protection to their patients.

Nicki elaborates:

'The patient and their families expect me to do miracles. They know (patient/family) they have failed to pay for their treatment contract agreement with the company. This is seen as a breach of contract and consequently the treatment is stopped. I can't call the doctor to see the patient and to give a prescription as I follow the company guidelines, you are caught in between.'

For this reason, the participants viewed that the most important personal goal was to apply their knowledge to the care of their patients. This care was disrupted by the healthcare system, especially for those nurses who were forced to terminate dialysis due to depletion of funds. This finding is consistent with Orth and Wieland (2006), who also related the feeling of anger as 'a perception that important personal goals are blocked by improper action of an external agent' (Orth & Wieland, 2006, p. 699).

Beauty related her story:

'What is the point of me being a professional nurse and a unit manager, knowing what's wrong with my patient but I can't help them? You take the nursing pledge to care for patients, but you can't do this because you are bound by certain criteria of the company's policy and guidelines and rules. You really feel disappointed' {pulling strands of her hair}.

In this study, the participants tried to negotiate for free dialysis sessions, however they were unsuccessful. The reason as to why free dialysis was declined might be the fact that the provision for dialysis in the private sector is based on affordability.' This is in line with the guidelines for chronic renal dialysis in South Africa which stipulates that 'renal replacement therapy is not freely available. Patients who can afford it or who have medical insurance may be able to receive these expensive therapies in the private hospitals' (South African National Department of Health, 2009, p. 5). This study underscores the hostility component of the anger described by Orth and Wieland (2006) who viewed hostility as an attitude and a tendency to hate and distrust others because one tends to regard the behaviour of those involved as selfish and cruel.

Nicki expresses her disappointment:

'For me it was sad because I am a nurse and I care, we care [raises her voice]. When I was a student, I wasn't aware of this, I thought that once a patient arrives, you must jump in and act. But what I am facing here is not what I learnt to do. I actually told the doctor that this patient will die [Shaking both arms] The doctor ordered us to refer the patient to the state hospital as his medical aid refused to pay and the patient died there.'

James states:

'{Face down, shaking his head} The company survives because of the patients over time. These patients have been with the company for a long time bringing money so suddenly the money becomes a problem. The patient serves no purpose to the company. Once there is no money coming in, the patient has no purpose. I was disappointed at the way the company treats patients when the medical aid is depleted.'

This ongoing emotion of shame and guilt exposed these nurses to emotional trauma. This finding is also in keeping with the description of shame by Wilson et al. (2006). Wilson and colleagues viewed shame as a 'deeply rooted sense of having violated one's true nature, no matter how accurately or inaccurately perceived by oneself or others.' They further highlighted that shame in its extreme forms, is a painful and draining experience' (Wilson et al., 2006, p.125).

James goes on further:

'Feeling useless, feeling powerless, I became very despondent. I felt I served no purpose in her life [with sad voice], {shakes slightly his head}. Our friendship became meaningless. No support as a friend. It is emotionally draining, it provokes your emotions. I am still angry for her death because of this selection criteria system. They kill our patients. They choose who lives and who dies' {bangs on the table}.

During the conversations, I sensed the nurse's feelings of anger, shame and guilt which were also discussed in Bratton's study. Bratton's study (2010) reported that a relationship exists between anger and shame and that these two variables play an important role in trauma response. Bratton (2010) further explained that those students who presented with a high level of shame were more likely to develop a post-traumatic stress disorder (PTSD) and were

less willing to seek psychological treatment (Bratton, 2010). In this context, Wilson and colleagues clarified that the shameful individual will display behavioural signs such as ‘turning away of the face, avoiding contact, downcast eyes, slumped posture, blushing, mind going blank, and arrested behaviour’ (Wilson et al., 2006, p. 124). My study allowed me to observe patients as avoiding eye contact and looking at the ceiling and correlated well with the Wilson et al., 2006 study. These signs were evident from the participants and it appeared that there was a considerable level of shame which could lead to PTSD.

Zola presented the signs of shame:

‘You don’t have a choice but to accept your weakness...Once this patient is kicked out, you have a new patient coming in his place, so work goes on’ {sighs deeply, lifts his shoulders and faces the ceiling}.

This study findings are comparable to Bratton’s (2010) study, as all the participants demonstrated a high risk of emotional trauma, but none used the counselling services provided by the dialysis provider company (ICAS). When I asked **James** whether the staff received emotional support after their patient’s death, he answered with anger:

‘The company should provide the staff with proper support not like that of the ICAS who do counselling over the phone. I see this as impersonal. Not really helping. You talk to a stranger over the phone for your stress. I never used it [With angry voice].’

The participants also experienced guilt which was evoked by the existing dependency-caring-relationship with their patients and their failure to relieve their suffering. This is in keeping with Strandberg and Jansson (2003), who explored the meaning of dependency on care in the medical hospitals in Northern Sweden. The authors reported that these nurses wanted to do all they could for their patients, but they viewed it as a taxing responsibility when they were unable to render quality nursing care to them. This induced ‘the feeling of guilt and inadequacy and of being constantly concerned and worried’ (Strandberg & Jansson, 2003, p. 88). Within this context, the concept of guilt is also described as ‘transgressions or failed behavioural portrayals for responsibilities regarding others’ and suggests that ‘guilt involves different forms of self-recrimination about accountability for personal actions’ (Wilson et al.,

2006, p. 123). In the current study, the patients and their families had been dependent on the participants as entrusted caregivers and friends for many years. When dialysis was withdrawn, and their patients were suffering, the participants blamed themselves as contributing towards the withdrawal of dialysis.

Beauty shares her experience

'Dying because of lack of funds, it is an unnecessary death. I am feeling guilty because I feel I should have educated my patient not to change his medical aid before making sure that the new policy is in force.'

This finding is consistent with Grönlund et al. (2015), who found that nephrology nurses felt responsible for the suffering of their patients, as they failed to initiate dialogue to inform the patients and their families about the dialysis complications. In my study, when there were no more funds, dialysis was withdrawn, and the nurses experienced feelings of powerlessness, hopelessness, guilt and shame. Feeling inadequate to alleviate the suffering of their patients after dialysis withdrawal, contributed to the guilt-related emotional trauma after their patients 'death due to the traumatic memories of their patients' suffering.

Zola expresses his sentiment as follows:

'I felt unhuman {pause}. I tried to send the patient to the state hospital where he had some sessions but later on he was kicked out due to the admission criteria. He came back to us, sufferin, from fluid overload and shortness of breath. Family paid for a few sessions but didn't last a long time and dialysis stopped completely, after few days patient passed on {pauses, shakes his head}' ... Zola

Bratton explains that guilty thoughts often follow the traumatic memories which are then accompanied by a negative emotional response such as distress, anger and guilt (Bratton, 2010). The author argued that the reason the shame and guilt feelings are so painful and 'do not improve over time, is the inability of people to directly correct or repair their wrongdoing or damage' which is not always possible (Bratton, 2010, p. 13). Within this context, **Queen** tried to justify her failed patient's care as follows:

'After my patient's death, I felt innocent {head down, hang on her arm on the table, closed eyes}, [sighs deeply, pauses]. But it broke me. But I did what I could {Wipes off tears}.'

Queen also relates her remorseful experience after the death of one of her nurses' patients who died after dialysis withdrawal and she refused her to dialyze him.

When I was informed that her patient died, I remembered the tears of that nurse who begged me to perform dialysis him and I refused. I felt very bad. I felt we could just dialyze him. The patient died {wipes off tears}

Queen's story captures her painful emotions when reflecting on her actions on her patient's suffering after dialysis withdrawal. **Queen** displayed shame and guilty emotions which still lived inside her memory. This fact clarifies why guilt and shame may be the major symptoms of the gradual development of PTSD, subsequent to emotional trauma experience (Bratton, 2010). This finding is also similar to the results of Dutch PTSD Scale based on Diagnostic and Statistical Manual of Mental Disorders (DSM IV) of PTSD criteria carried out by Hovens et al. (1993). Hovens and colleagues' PTSD Scale assessed the Dutch Resistance Veterans of World War II and their findings revealed guilt as one of the factors linked with PTSD. The veterans guilty feeling was due to being exposed daily to suffering and death during the war (Hovens et al., 1993, p. 200). The authors indicated that amongst other factors, the feeling of guilt was a significant factor of an emotional trauma response. In my study, the participants were in constant contact with their patients suffering and were powerless to help relieve or intervene to alleviate their patients' pain both physiologically and psychologically. When I asked **Nicki** about what she found difficult in caring for her patients with ESKD after dialysis withdrawal, her answer was:

{Shaking her head}, 'When I think of my patient's suffering, shortness of breath and his swollen face, I really feel guilty. As a registered nurse with my dialysis experience I could have done more. Not being able to dialyze my patient while I had all the equipment but because of company restrictions, that was a disappointment.'

And Zola says:

'After dialysis withdrawal, I watched him getting gradually sick and his condition deteriorated until death, knowing that I could have saved his life if I had the means; that was bad {folds his arms around his waist and face the ceiling}.'

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During the phenomenological conversation with the participants, the experience of witnessing the suffering of their patients, revealed the extent of their own personal suffering. Combining the literature and the phenomenological conversations with the participants made me understand why the participants were acting in such a manner. Some of them manifested gestures as a way of expression of their suffering and others were just quiet for a moment, while others cried. This study offered them the opportunity to communicate their own suffering while caring for their patients' suffering after dialysis withdrawal. Furthermore, our conversations created a platform for them to release some of their internal heaviness and realize that they needed assistance in order to cope with emotional trauma. For this reason, two of them needed counselling soon after our first phenomenological conversation.

At the time of doing the literature review, I had not explored the topic of 'suffering expressions.' My phenomenological conversations required me to delve into this concept of suffering expressions. The information I found revealed similar findings described in literature (Ferrell & Coyle, 2008; Perry, Toffner, Merrick, & Dalton, 2011; Reich, 1989). The finding in my study appears to be consistent with the three phases of suffering identified by Reich (1989). The author clarified that the sufferer will go through; (i) 'a mute phase' in which the 'sufferer' is incapable of expressing emotions, then (ii) 'the expressive phase' in which they attempt to find a language and use gestures to express that suffering and finally (Polit & Beck, 2017) the 'sufferer' adopts a new identity in suffering and determines an appropriate voice to express one's own suffering (Reich, 1989, pp. 86-91).

Reich explained that sharing one's 'own suffering serves two major purposes.' (Reich, 1989, p. 89). Firstly, by talking about the past traumatic experiences, the sufferers developed acceptance of the reality and a distancing from the experience –thus their perspective on caring for patients with dialysis was changed to a more accepting attitude about the reality of death. Secondly, the narratives offer hope for the future that the listener will reaffirm a justification of their suffering, thus, allowing them to seek help. At the time of the phenomenological conversations feedback, one participant reported that she had started counselling with ICAS, while another was considering consulting a private counselling service. By their seeking counselling as an intervention, I interpreted this a form of offering relief from their suffering experiences.

Moral distress

In this sub-theme of psychosocial effects, the theme cluster of '*moral distress*' was identified in all the participants' narratives. During the phenomenological conversations, the participants viewed suffering of their patients as preventable. They expressed that the most common cause of dialyses withdrawal was due to financial constraints, which made it difficult and even impossible to render care to their patients. Despite being informed that the patients could not receive dialysis or any other medical/nursing intervention, they continued to come to the healthcare facility with their families, in the hope that something could be done.

Beauty narrates her experience:

'Being bound to policy and guidelines makes you sometimes feel that you are dehumanizing patients. Continuously seeing the patient coming into the unit to try his luck if anyone can put him to the machine, this was the most devastating situation.'

Grönlund and colleagues admitted that nephrology nurses experienced more moral distress and dilemma when they could not intervene to relieve the suffering of their patients (Grönlund et al., 2015, p. 719). Some patients presented themselves to the dialysis units in

hope that their suffering may be alleviated, but the nurses' turned them away which left a feeling of failure, which contradicted their moral conviction of 'caring' as 'being with' as defined by Parse (1988). The concept of caring 'being with' is explained as 'encountering or reflectively attending to the other' (Parse, 1988, p. 131).

The participants in my study chose to engage with their patients in an open, authentic relationship by offering their 'wholeness' to the 'wholeness' of their patients together with bearing the responsibility of nursing care (Parse, 1988, p. 131). By sending their patients home with a life-threatening condition, moral values of caring which is associated with being a nurse was brought into conflict. This moral dilemma caused a troubled conscience followed by feelings of inadequacy, helplessness, guilt, shame and on-going emotional distress.

Queen says:

'Yes, they are sent home to die but because their families also don't know what to expect. When their conditions deteriorate, they rush them to the nephrology nurses in the units as they can't be admitted in the trauma or ICU, due to no medical funds.'

The findings in my study correlated with Grönlund and colleagues who described that nephrology nurses had a 'troubled conscience' as 'the result of a merger of the *life-world* of the nurse with the *life-world* of the patient' (Grönlund et al., 2015, p. 713).

Hopelessness

The emotion and inner sense of hopelessness was another theme-cluster that was revealed as an experience of emotional trauma among the study participants. They were left helpless when they found out that their patients were withdrawn from dialysis. This 'helplessness' was not only physically and mentally exhausting, but also left them with feelings of frustration and despair. The participants tried to advocate for their patients but failed, leaving them voiceless.

This failure led them to experience emotional trauma as all they could think of was the imminent death of their patients.

Nicki said:

'I failed to advocate for the patient. I knew that no dialysis, no life for ESKD, patient. Seeing the conditions deteriorating, you can see that the person is dying so I just started seeing death on him'

Queen shares her story:

'I tried to phone all over to get help. I really felt helpless that we could not refer my patient anywhere else for treatment until she passed on.'

These findings are comparable with Kim and colleagues who described the lived experience of nephrology nurses caring for their patients with ESKD as those nurses who provide caring for the patients with terminal diseases such as cancer (Kim et al., 2016). In their findings, the authors highlighted that nephrology nurses go through the same emotions as oncology nurses as they all care for patients with incurable diseases. The study participants experienced feelings of hopelessness, depression, pain, frustration and feeling incompetent. These feelings came about when they could not do anything to lessen or slow down renal failure or at the very least, find help from elsewhere.

Physiological effects of emotional trauma

The theme-clusters identified in this sub-theme were (i) insomnia; (ii) fatigue; (iii) difficulty concentrating and (iv) aches, pains and muscle tension.

Insomnia

In this sub-theme, the aspect of '*insomnia*' was verbalized by all the participants. They expressed that during their sleep they had a recurring image of their patients suffering whilst they were dying. This caused the participants to have recurring episodes of insomnia.

Honey shares her experience:

'I constantly reflect about the reactions that the patients had after breaking the news that nothing else could be done to get the dialysis access. One patient's response was:" but Sister I don't want to die." {Wipes away tears}. I don't sleep soundly, and I sometimes get up and go into my lounge and cry.'... Honey

This fact of emotional trauma experienced by the participants is in keeping with Castles and Murray's writings (1979) in their book '***Dying in an institution: nurse:patient perspective.***' The authors stated that following the deaths of their patients, nurses suffer from a personal loss because of prolonged countertransference in the relationship between nurses and patients (Castles & Murray, 1979). Furthermore, Castles and Murray acknowledged that the nurses experience the impact of death 'more than once, in more than one role and with different intensities' (Castles & Murray, 1979, p.23).

Fatigue

In this sub-theme, the participants also found this type of care to be physically exhausting and interpreted as being '*fatigued.*' This was the result of what is termed as 'compassion stress,' an adverse effect of a constant experience of others' suffering. This effect was also described by Showalter (2010) as a condition in which nurses and other healthcare professionals get affected by the impending deaths, illness, trauma loss and grief of their patients. This is seen as secondary trauma. The participants witnessed their patients suffering but were unable to intervene and rather turned them away. This fact resulted in them suffering a 'compassion stress'.

Beauty expresses herself in the following sentiment:

'The ups and downs during the day, sorting out medical aid and finance problems and attending to the family members is hectic' {bangs her hand on the table}. ... Beauty

Aches, pains and muscle tension.

The theme cluster of '*aches, pains and muscles tension*', was another aspect of the physiological effect of emotional trauma on the nephrology nurses, identified from the phenomenological conversation. This was interpreted by the fact that they were exposed to their patients 'suffering and was unable to deliver patients 'care to relieve their suffering. The nurses' distress of being unable to deliver patientcare was revealed in the following narratives:

Beauty narrates her stress experience:

'It was stressful moment to see the patient coming to hear the feedback from the medical aid and waiting for you to say something positive. Patient was told that he will be phoned for the medical aid outcome, but still coming to the unit without being called. He asked me "I hope you got good news for me?" {cries...}.'

Nicki stated:

'You spend a lot of time running up and down, trying to get help and care for other patients, at the end of the day your legs and back and neck are painful, you suffer from migraine and many more. It is hectic I don't like to have this situation.'

Vermunt and Steensma (2005), stated that stress occurs among individuals when there is a discrepancy between demands and the particular individual's ability to fulfil those demands. Stress leads to aches and pains which can be behavioural, psychological and physiological response to the stressors. Furthermore, this may result in chronic sicknesses, if the individual is exposed to stressors for a prolonged time (Vermunt & Steensma, 2005).

These nurses, being empathically connected to their patients suffering, experienced cumulative stress which intensified physical symptoms including aches, pains and muscles tension. Professional caregivers who were exposed to ongoing mental, emotional and

physical stress, often developed physical symptoms including ‘headaches, gastrointestinal disorders and muscle tightness’ (Showalter, 2010, p. 240).

Difficulty in concentrating and withdrawal from social engagement

The participants reported to have persistent thoughts and images related to their patients suffering, even when they were sleeping or relaxing. This caused them to experience difficulty in concentrating on their normal tasks as they were consumed by their patients suffering. All who were interviewed reported that they could not concentrate on caring for their other patients, when their other patients were outside suffering and begging for dialyses.

Honey told me:

‘As unit manager, every time there is a patient taken off from dialysis; I keep on thinking about the patient’s suffering and I can’t catch up with my administration work. The thought never subsides.’

And **Zola** said:

‘You can’t focus on your work when you see someone outside the unit suffering and being short of breath and swollen, begging for dialysis.’

Most of the participants (6 out of 8) reported to have lost interest in some social activities with their families and friends. Some preferred to stay in bed on their day off and on the weekends.

Milani expressed herself:

‘I normally make nice food for my family when I am off. But when my patient passed away, I felt numb and very weak. I felt I needed my space. I was just thinking about him struggling to breathe. My children and my husband know me when I am in that state. They leave me alone.’

The findings of my study are similar to those identified by Showalter (2010), who reported that healthcare professionals manifested various symptoms that might impair concentration. The author stated that these professionals experienced symptoms such as 'depression, withdrawing from family and friends and losing interest in things they once enjoyed' (Showalter, 2010, p. 240). The author reported that having persistent thoughts and images related to the problems of others, might lead to distraction in professional and personal lives of nurses (Showalter, 2010, p. 240).

Occupational stress effects of emotional trauma

In the sub-theme of '*occupational stress effects of emotional trauma*', three theme-clusters were identified, (i) scapegoat and finger pointing; (ii) exclusion from decision-making and (Polit & Beck, 2017) self-expectation and reality.

Scapegoat and finger pointing

In this sub-theme, the concept of '*scapegoat and finger pointing*' experienced by the participants was interpreted as victimization. The participants had to endure the consequences of dialyses withdrawal, because of deteriorating renal function. They were seen as at the frontline to answer questions from distraught patients and their families, as these patients could no longer be seen by the nephrologists or the healthcare provider.

'It is a stressful moment as you are at the frontline to deal with those conditions, including pressure from the patient and family. Then you must explain why the patient cannot be dialyzed and then give advice and still abide by the policy of the company. You actually start grieving for your friend because you know this is the end.'... **Zola**

If dialysis withdrawal was due to access failure, the participants said that the patients were sent to them by the doctors knowing that there was nothing else that could be done. In these instances, the patients and the family members looked at them as they were the ones who did not know what to do. Should the problem be due to medical funds depletion, the patients

and families were still returning to the units expecting the nurses, as their friends, to dialyze them.

The participants felt as if they were a scapegoat as they had to endure someone's else's problem. They mentioned being blamed by the medical staff as being the cause of the depletion of the patients' medical funds together with dialysis access failure. From their narratives, it appeared that the medical staff blamed the nurses for the increased hospital admissions. These increased admissions were mostly from infection and fistula damage which caused medical funds to run out. The participants shifted some blame onto the medical staff who contributed towards financial depletion because of the ordering of unnecessary blood tests and other investigations.

Milani relates her experience:

'You are the last person to be there. Doctors failed, system failed, and it all comes back to you. Whatever went wrong either from patient's side or from treating by the team side, you have to bear it all.'

And **Beauty** said empathetically:

'The family was not happy with all the processes. They were coming to me as I was the unit manager. It was like they wanted the money that they had spent on dialyses returned to them. One cousin of a certain family said, 'you guys it is all about money, look at how much money we have spent but you can't even help him, after all that money we have paid?'

The findings by Thomas (2008) who reported that nurses are blamed for the 'mistakes and omissions' of other healthcare workers were similar to the findings of this research study (Thomas, 2008, p. 13). Thomas stated that when the physicians get into a situation which might upset the patient's family, they shift their responsibility to the nurses, hence blaming them for the consequences. Following dialysis withdrawal, participants in my study experienced a constant blame from both the medical staff and patients. This resulted in increased anxiety, especially since the nurses were aware of inevitable death which in turn also led them to experience emotional trauma.

Exclusion from decision-making

Another theme-cluster in this sub-theme was the '*exclusion from the decision-making*', in which the participants perceived their role as unrecognized and excluded. The admission of patients and withdrawal of dialysis was not inclusive of a team decision involving healthcare provider, medical staff and nursing staff. The participants felt that with the nursing experience that they had developed in this nursing specialty, and the relationships that they formed with the patients and families, they were better equipped to assess what the best intervention for the patient and family's interest would be but were unfortunately excluded from the decision-making progress.

For example, **Queen** related her following story about a patient who became a significant other to her:

'She was more than a patient to me. We shared many things. We came a long road together. She took me in as her daughter and she always mentioned to me that I am the daughter she wished to ever have. Her, being Muslim like me, I always gave my donation to the poor to her, as this is the culture of all Muslims, to give to the less fortunate during the fasting period every year. I knew her family and they knew me too. They called me 'Mrs. Social Worker' [laughs ...]. When her husband came to drop or fetch her, he always made sure to talk to me. But when she got sick, he dumped her [starting to get teary eyed].'

The participants argued that due to the relationship they developed with the patients and the families, they already knew those patients who were financially struggling. To be included in decision making would have allowed them to reduce the amount of dialyses sessions of these patients, while maintaining a strict diet and health education. However, as they could not decide, their patients ended up depleting the medical funds and were excluded from treatment and faced imminent death.

Queen narrative's captures this sentiment in the following statement:

'If dialysis was withdrawn gradually, we could have kept my patient a bit longer. It was sad to lose my friend' {closes her eyes and shakes head}.

The participants felt remorseful in having acted against what they believed was good for their patients, even if this caused suffering and death. This inevitable consequence to end suffering was conveyed in the experience of two nurses. Their experiences also caused emotional trauma. In this instance **Jane** stated:

'Following the doctor's orders was not a choice. But it was not worthwhile withdrawing my patient gradually. I knew exactly that he will not make it. Treatment should just stop and then carry on with end of life care.'

Honey also relates a similar story regarding her patient who was withdrawn dialysis, due access failure:

'The access was getting worse every day and we could see where we were heading. Death was clear, there was no hope to recover. I wish I could make a final decision. I would rather stop completely. We called the doctor to come and see how we were struggling but the medical staff ordered us to carry on.'

This finding in my study correlated to those of Grönlund and colleagues, who reported that when registered nurses worked in haemodialysis, they were faced with difficult situations and as such they tried to call for a 'deliberative dialogue' with those involved. This dialogue allowed the nurses to share their uncertainty and clarify their concerns. However, the physicians who were the decision-makers, showed no interest in their concerns which made the registered nurses to feel 'belittled, abandoned and disempowered' (Grönlund et al., 2015, p. 719).

Self-expectation and reality

The *self-expectation and reality* was another theme-cluster within the sub-theme of occupational stress effects of emotional trauma. The participants felt that their expected role as care givers was a challenge as good nursing care could not be given. They never thought that a patient could be turned away without any treatment, whilst the patient was still suffering. The participants felt powerless and unable to alleviate pain and suffering of their patients as they could not make any changes to the situation.

Milani narrates this in her following story:

'You come here for patient care. You show the patient the door {extends her arms wide}. When the condition of the patient doesn't look good, you as a nurse, you call the Doctor for help. But now in the case of 'dialysis withdrawal' –the Doctor's order, there is no one else you can run too.'

The findings in this study is consistent with Grönlund et al. (2015)'s study investigating the 'ethical difficult situations in hemodialyses care.' The authors reported that the registered nurses in dialysis could not protect the dignity of their psychotic patient's due to their powerlessness to change the dialysis schedules. Also in their study, the registered nurses expressed their stress when they could not increase the dose of analgesics for their patients with a severe pain due to the physicians 'restrictions (Grönlund et al., 2015). In my study, the participants perceived the turning of their patients away from dialyses as overwhelming. When they heard about their patient's deaths, they felt guilty and blamed themselves as being associated with the cause of their deaths. This exacerbated their emotional trauma.

Queen expressed her emotions in the following statement:

When I got informed that the patient died, I remembered about the tears of that sister who begged me to perform dialysis on him and I refused. I felt very bad, I felt I could just let her do it, but it was too late as the patient had died {wipes off tears}

Zola stated:

'To continue to follow up on the patient after dialysis withdrawal, makes the family to feel that you care and makes them to keep on bringing the patient to the unit hoping that you will help. When you see them, you get worried and feel guilty, as there is no chance to get the patient onto the machine.'

5.1.2. Main theme 2: **Detachment**

The nephrology nurses, having felt that they had failed their patients, anticipated that death was the inevitable consequence. It was at this stage that the nurses began to detach themselves physically and emotionally from the patient and their families. All of the

participant nephrology nurses expressed themselves by using avoidance as a coping mechanism to detach from their dying patients and their families. This theme comprised of two sub-themes of (i) nurse-patient detachment and (ii) nurse-family detachment.

Nurse-patient detachment

In this sub-theme, three theme-clusters were generated from the participants narratives; including; (i) personal detachment; (ii) professional detachment and letting go.

Personal detachment

When the nurses in this study realized that their patients were going to die, they started to say goodbye to them, hence, gradually detaching from them. They considered the process of detachment as a difficult situation, as they had to deal with the reactions of the patients and their families after breaking the news regarding dialysis withdrawal.

Honey reflected on her patient's reactions in the following statement:

'I constantly reflected on the reactions that the patients had after alerting them to the fact that nothing else could be done to get dialysis access. One patient's response was, but sister I don't want to die' {wipes away tears}.'

Nicki related her story about observing her patient's conditions worsening:

'Seeing the conditions deteriorating, you can see that the person is dying so I just started seeing death in him. When I saw him coming, I rather asked someone else to attend to him.'

The nurses reported to have experienced emotional trauma as they watched their patients' conditions deteriorate and as a result, were no longer able to attend to them. Realizing that they were unable to intervene to stop their patients' imminent death, they walked out of the

relationships they had with these dying patients. This was a coping mechanism for them to prevent the subsequent emotional consequences from building up inside them and to rather care for the other patients who were still had dialyses access. This process of patient detachment was also reported by Missouridou (2017), who described the detachment of health care nurses as 'an emotional reaction to suffering patients.' The author explained that the healthcare providers chose to end the relationships with the suffering patients to prevent 'horror and many other strong emotions which were difficult to bear' (Missouridou, 2017, p. 112).

My findings also supported Davies et al. (1996) who viewed reported that most of the nurses who developed a close relationship with the dying child suffering from numerous diseases, began to withdraw from the child and the family (Davies et al., 1996). In this study, some participants reported that in order to terminate their relationships with dying patients, they found comfort in meditating on the good care they had provided to their patients in the past prior to dialyses withdrawal. **Queen** stated the following:

'I have been with her for eight years, I cared for her as my own mom, she was dependent on dialysis for her whole life, but now that she died she has no more pain, may her soul rest in peace.' {cries} ... **Queen**

Professional detachment

When the dialysis was withdrawn, the nurses shifted their healthcare role to advocacy and finance. The participants who cared for the patients, who were withdrawn from dialyses due to fund depletion reported to have spent more time in negotiating for free dialyses sessions with the healthcare providers, rather than attend to their patient care duties. They also had to mediate between the patient and the medical aid institutions. Seeing that all they tried had failed and that their patients 'death was imminent, they perceived the private dialysis practice as frustrating and some of them were planning to leave this nursing care specialty.

James narrated his experience

In the private healthcare system, mostly dialysis is withdrawn because of funds. As dialysis is withdrawn, the eventuality is death and it is very frustrating, no matter what hope you can give to the patient. You are helpless because you know the client is going to die and you have no means to continue dialysis.'

This finding is in accord with the study of Schluter and colleagues who stated that failed efforts to advocate for patients, produced strong feelings of moral outrage and distress (Schluter, Winch, Holzhauser, & Henderson, 2008). Overall the participants indicated that the cause of the death and its subsequent blame was difficult to bear. There was a situation of blame between doctors, the dialysis provider companies, the healthcare system and the nurses. The surgeons failed to create working dialysis access and the physicians ordered unnecessary tests which depleted patients 'funds. The dialysis provider companies refused to offer free dialysis sessions and did not follow up on time the patients 'medical funds until it was depleted. The healthcare system admission criteria rejected their patients. The participants also mentioned that the nurses themselves contributed to the patients 'medical fund depletion due to increased hospital admissions caused by infections and dialysis access damages (AVF and dialysis catheters).

This was captured in the following statements:

'I blame the health system and the state criteria because this patient could have survived, if it wasn't for that admission criteria.'... **Honey**

'Nurses are also blamed by the doctors and patients for causing the hospitalizations due to infections and lack of patients education regarding their dialysis access damages.'... **Beauty**

This finding is also similar to the study of Davies and colleagues who stated that when it became clear that the child (patient) was going to die, 'the child's death often conflicted with the reality of the active treatment regimen for the child' (Davies, 1996, p.6). Nurses blamed the doctors for not doing what they sensed could be in the best interest of the patient and this caused them to experience moral distress (Davies, 1996). The nurses in my study, also

blamed themselves when their patients were withdrawn from dialysis. This self-blame was especially more evident in managerial staff who had to endure more blame from their staff. This blame was evident when I asked **Queen** to relate how the care of patient with ESKD withdrawn from dialysis, had affected her professionally; she responded in tears:

{Teary} As a unit manager I lost trust in my junior staff. One day a sister approached me and asked me, "Sister can we not dialyze this patient? Nobody will know, just between us." My answer as a manager was that it was unethical, as there was no doctor's prescription and it is stealing the company money. The nurse was in tears. It is a dilemma you have to face, as you have to care for the patient and still abide by the policy of the company.'

These emotions had a negative impact on the participants regarding patient care delivery. They all had acquired the attitude of detachment from their patients to prevent any other kind of bond forming, and the three of them were planning to seek for employment in a less stressful area of nursing. These nurses related their stress as specifically associated to the denied care of their patients who became their significant other. This is a new perspective regarding the concept of detachment as I found no supporting literature specific to nephrology nurses in this context.

Nicki shared her emotions:

'Yes, this dialysis is frustrating. I am planning to look for a job somewhere else like in psychology or maternity. When the patient gets seriously ill and gets transferred to the appropriate level for further treatment, it is out of your hands. But when the dialysis is withdrawn, there is nowhere to transfer the patient until death.'

Zola stated:

I am actually thinking of leaving this career to study something else. It is difficult to carry on this way because it is not easy to get rid of your patient in your mind. The moment you are still thinking about your patient whose dialysis was withdrawn, you get a new one to care in his place while waiting for that one to die.'

There are numerous studies exploring nurses 'intention to leave the profession due to job dissatisfaction and burnout as a result of their working environment, less payment, organisational structure and moral distress (Dagget, Molla, & Belachew, 2016; Dereen Houck, 2014; Grönlund et al., Thomas, 2008), however there is no study reporting that nurses wished to leave their jobs because of the deaths of their patients. This is another area of a nursing stressor that require further research in the area of nephrology nursing.

Letting go

The nephrology nurses in this study stated that once dialysis was withdrawn, they were aware of their patient's imminent death. The participant nurses admitted to the failure of caring for their patients and accepted their death. They all acknowledged that their patients were suffering and there was no means to alleviate their suffering, therefore confessing that it was better for them to die than to suffer. This made the participants in this study to experience an early relationship closure with their patients and to begin mourning, even before their patients died. This premature mourning was seen as a way of letting go.

Nicki stated:

'Patient was dying because of the cost and I had no means to pay for his dialysis, I just prayed for him to rest in peace where he will never suffer anymore' {sad voice}.

This finding offered a new perspective to the concept of detachment, although there was no evidence in the literature relating to nephrology nursing. The care of the patient after dialysis was withdrawn also provided a time for the nurses to separate themselves from their patients, especially when there was an existing bond formed. However, all the participants expressed that this separation was difficult as they perceived the deaths of their patients could be prevented. They all viewed these deaths as unnatural and that this awareness made them to prematurely terminate the relationship with their patients before death.

Zola related a story about his patient begging him for dialysis:

'It is embarrassing to see your patient who was on dialysis for a long time, coming to beg to be dialyzed, getting sick and deteriorate in front of you while you could have prevented it, so I rather avoided him.'

This finding in my study was in contrast to literature about the patient-relationship journey. For example, Parse explains that 'caring' is '(i) risking and (ii) being with someone towards a moment of joy' (Parse, 1988, p.130). During caring, nurses aim to constitute an open and authentic relationship with the patient, providing a medium through which both can grow in friendship. The participants took a 'risk' to build a relationship with their patients because of the imminent death which followed (Parse, 1988, p.130).

This is explained in the following narrative by **Zola**:

'My patient was on dialysis for a long time and was known as a non-transplantable patient. His life depended on dialysis. I had a conversation with him, chatting not only about health education, but also on social issues which lead us to form a bond between us.'

The concept of 'being with' of caring, was created between the participants and the patients as the participants opened an authentic engagement by offering their wholeness to the wholeness of the patients. This also allowed the participants to bear responsibility and to participate with patients in their health-related situation (Parse, 1988, p.131).

Beauty highlighted this as follows:

'Since I am a parent like him, we were talking about our families. I felt he was going through the same situation as me, of being disappointed by my partner. This relationship with him facilitated our closeness and showed me that people don't care how much you know unless you show them how much you care. Then you remember something about them.'

Lastly, the concept of 'moment of joy' was explained as being the 'complementary rhythm of suffering-joy all at once'. Here Parse clarified that nurses having been with the patients during their suffering-joy allowed them to grow (Parse, 1988, p.131). In this phase, both nurses and

patients had some form of hope through which a growing relationship with each other was seen as a joyous occasion. Unfortunately, after dialysis withdrawal, their relationships stopped, and this was a cause of great disappointment and was far from being an enjoyable moment. **James** expressed his experience:

'When dialysis stops, the friendship stops. First of all, your patient is angry with you, you are not doing something to help him. You are a friend, but you can't even put me on the machine? You are failing the patient. It is disappointing to the patient and to yourself.'

The *'letting go'* process made the dying process of their patients difficult, as they died hopeless. In this study, the participants did not get a chance to apply that role of a healer and did not enjoy this moment of the journey with their patients, rather their *'letting go'* moment was perceived as stressful, disappointing and laden with fear, guilt and blame. The nurses also claimed that their patients did not enjoy their passing moment, as none of their carers prepared them and their family to view death as a healing event. They (patients) rather experienced anger and retaliation against the dialysis provider company and the medical staff.

During the dying moment, hope was described by Kübler-Ross as a central characteristic in the psychology of dying (Rosa et al., 2017). Kübler-Ross referred a *'well-prepared grief process'* as healing care which is provided by nurses who were considered as *'healer agents'* ((Rosa et al., 2017, p. 61). Kübler-Ross acknowledged the curative approach as healing but criticized it as not always being possible to provide a complete healing. Conversely, she described healing care as a multidimensional approach which is always possible and can occur on an *'emotional, mental, spiritual or physical'* platform (Rosa et al., 2017, p. 61). From this perspective, Kübler-Ross explained death as a *'healing event'* which occurred in the other non-physical domain of life' (Rosa et al., 2017, p. 61) and Hertz (2013) called *'death'* the passing of the soul to his *'happy home'*. The findings of my study is an area for further research.

Nurse-family detachment

This was another difficult experience the participants endured. The participants in this study felt that they were seen in a bad light by family members as dialysis was withdrawn. Therefore, the participants were not able to communicate with them in order to offer any support during this difficult moment. In this scenario, the participants and their patients' families did not allow them to offer a good preparation for a good death of their loved one as recommended by Pattison (2008). In this sub-theme, two themes clusters emerged from the participants 'narratives; (i) fear of being hurt and (ii) avoidance.

Fear of being hurt

The reactions of anguish and frustration of patients and their family members made the nurses to feel helpless and vulnerable. Participants said that they were at the forefront of facing all the consequences of the dialysis withdrawal, as the patients and their family members claimed that it was them (participants) who did not want to dialyze the patients. The participants mentioned that the family members felt that they have paid more than enough to keep their patients alive. The participants felt threatened and tried to disconnect with the family.

Beauty related her experience in this context as follows:

The family was not happy with the whole process. And all were coming to me as I was the unit manager. It was like they wanted back the money they have spent on dialysis before. The cousin said, 'you guys it is all about money, look at how much money we have spent but you can't even help him from all that money we have paid?'

I found this to be a finding not reported in the literature. Conversely to other studies, in normal circumstances when curative treatment becomes impossible, the nurses prepare and support the family to move to the 'non-physical level of healing' (Hertz, 2013; Kübler-Ross, 2008; Kuebler, 2001; Rosa et al., 2017). In my study, it was not possible to communicate with

the family members as all were very angry with the medical team. All of the participants indicated that they were afraid to face their patient's family members after dialysis withdrawal and after their death. This is captured in their following narratives:

'The family members were angry, they don't understand that they were not paying you.' ...

Zola

I was lucky I moved from that unit. After her death, I thought this man will come back to the unit to look for me because I was angry with him and it was like harassing him to pay for his wife's dialysis.' ... **Queen**

Avoidance

Another theme-cluster in the sub-theme of family detachment was identified as 'avoidance'. This concept was identified from the narratives of the participants as they all indicated that after dialysis withdrawal, they perceived a sense of being unfaithful and worthlessness in front their patients 'family members. This was due to the bond created between them and their patient's family members during dialysis treatment. **James** provided an example of such an experience as follows:

'The family knows you and they bring the patient short of breath and swollen to the unit and you say that you can't dialyze the patient, it is really a distress that I don't know how to explain that {head down}, there is no way to express that distress.'

The avoidance was a challenging moment for the participants as they had to find a way to detach themselves from the family and terminate that existing nurse-family relationship. In this context, the participants employed avoidance as moral justification of their failure to advocate for their patients (Childress, 1979). All the participants indicated that they felt as if they had failed their patients and that their deaths could have been prevented.

Honey explained:

'The nephrology nurses don't create the access, I felt disappointed by the system as they really couldn't make a plan for us to dialyze this patient or plan for kidney transplant.'

And **Jane** re-iterated:

'The system we work in fails patients with kidney disease. Yes, we can't fix everything, but something must be done for the patients with kidney disease. I am a nurse, I can only dialyse the patient, not access failure.'

This in accord with Childress who explained that in the avoidance process 'a person invokes conscience in the course of explaining acts that require explanation because they contravene the normal and established expectations' (Childress, 1979, p. 328). The author also stated that a person who is using avoidance for justification of his acts, tries to indicate that he considered all things and reassessed his standards before taking such a decision (Childress, 1979). This was seen as a defence mechanism utilized by the participants in this study. Furthermore, Childress clarified that the motive of acting in such a way is 'in part an avoidance of a sanction imposed by the self on itself' (Childress, 1979, p. 328).

The participants in this study felt some association with the deaths of their patients. This made them to judge themselves and ask themselves if there really was nothing else, they could have done to prevent the death of their patients? Therefore, they were associating themselves with the cause of death of their patients which made them to feel unworthy of a continuing relationship with their family members who knew them as care givers and best friends.

'The family knew me being closer to her, she used to introduce me to them as her nurse and a friend, so it was not easy to face them after her treatment was withdrawn and she died.'...

James

5.1.3. Main Theme 3. Loss of Altruistic Values in Nursing

Altruism is seen as taking care of the welfare and well-being of others (Fahrenwald et al., 2005). The participants narratives revealed that they felt hindered in practicing the altruistic values of nursing, primarily because of resource constraints.

Resource constraints

The lack of resources was perceived as the biggest obstacle in providing care to the patients. In this sub-theme, the following three theme-clusters were identified from the participants' narratives: (i) patient's finances; (ii) human resources and facilities.

The patient's finances

The lack of financial resources impacted greatly on the delivery of patient care and the participants felt that as they were advocates for their patients, they had failed them. This concern was expressed by five of the eight participants. The participants were distressed when they had to send their patients back home knowing that without dialysis they will die. In the phenomenological conversations, their narratives revealed their emotions of altruism and empathy towards their patients. However, the act of turning them away in a life-limiting condition was seen as an 'executioner' rather than that of a 'protector.' Here the participants felt overwhelmed by their powerlessness to practice the altruistic values of nursing.

Nicki explained:

'It is stressful to be in front of a patient and their family who was with you for more than five years, telling them that you are not going to dialyze. They think you are the one who refused to dialyze the patient. No dialysis, no life for a patient with kidney disease.'

Zola stated:

'You don't have a choice but to accept your weakness. Once this patient is kicked out, you have a new patient coming in his place. So, work goes on.' [sighs deeply], {lifts his shoulders and faces the ceiling}.

The role of being a nurse includes patient advocacy and protection from harm and negligence (Davoodvand, Abbaszadeh, & Ahmadi, 2016; South African Nursing Council, 2013). Davoodvant and colleagues, exploring clinical nurses' viewpoints on patient advocacy, identified two themes: *'empathy with the patient'* and *'protecting the patient.'* In the theme of *'protecting the patient'*, the sub-theme of *'taking care of the patient'* which emphasized the importance of patient protection against harm that may occur whilst in their care (Davoodvand et al., 2016). The authors argued that this harm might occur due to various risks, including *'physical, mental, deliberate, inadvertent'*, or due to *'insufficient or incorrect treatment'* (Davoodvand et al., 2016, p. 4).

The findings of my study supported Davoodvant and et al as the participants tried to advocate and protect their patients against the danger of discontinuing their treatment but unfortunately, they were not capable enough to challenge the situation. When their patients presented themselves to the units, the participants knowing that they were not eligible for any dialysis, dismissed them from the unit and sent them back home where they later died. This was a role shift, from a 'protector' to an 'executioner'. There is no evidence in the literature to support this and is my opinion only.

Honey related:

'To tell your patients that they can't be dialyzed due to no funds, is like throwing cold water on the person's face. It is like a death sentence.'

Beauty relates:

'I get agitated with the staff, when they ask me a favour to dialyse a patient with no funds or to patients who turn up to the dialysis centre, while knowing that they are not eligible.'

James related:

'If there is no money, no treatment.'

Manpower

Manpower (human resources) was viewed as another barrier to the altruism of nursing. Altruism reflects not only the welfare of patients, but also of other nurses and healthcare providers (Fahrenwald et al., 2005). The participants felt excluded when their patients died. They expressed themselves that as a result of a shortage of nurses and dialysis personnel, they were unable to have time off from work in order to grieve and mourn. This experience was captured by **James**:

'You have to come to work after your patient's death. There is no time to grieve as there is no one to replace you. Nursing shortages is always a problem. You just grieve inside and carry on caring for the other patients.'

The lack of human resources also had a negative impact on the participants as not being able to attend the funeral or memorial services of their patients. This resulted in a longer grieving and mourning period.

Jane explained:

‘Yes, I am still mourning and grieving for him. I used to watch cricket with him, and even today when I am at work and cricket is on TV, I remember him and realize that he is not there anymore.’

Jane’s statement demonstrated her mourning for her patient whose memory still lives inside of her, as she has been unable to have some form of closure to break the bond that she had had with him. The act of attending the funeral and memorial services could allow the participants of this study to demonstrate their respect to their patients who had become significant people in their lives. Hertz (2013) also suggested that attending the funeral and memorial services may allow the dead patients to free the families and friends from the obligations of mourning. This may possibly reduce long periods of grief for the family and friends.

The facilities

The lack of dialysis facilities to transfer patients from private to public healthcare institutions was another issue raised by the participants. Within the other disciplines of nursing, critically ill patients are transferred to appropriate healthcare institutions for interim treatment. In the case of patients with ESKD, this was not an option. Should there be no dialysis facilities available, then the patients will eventually die. This was a challenge for these participants as they were ‘resourceless’ to refer their patients for any treatment.

This finding of ‘resourceless’ is similar to that of Davison et al. (2015) and Fassett et al. (2011) who reported the lack of appropriate patient’s care after dialysis. For example, in South Africa, palliative care is focused on patients with HIV and cancer rather than patients with other non-communicable diseases including kidney failure, diabetes, heart and lung disease (Lohman, 2013).

The participants were overwhelmed when their patients presented themselves to the unit in a life-threatening condition. They were unable to render basic nursing care as there were no beds or spaces available. The participants indicated that once a patient is withdrawn from dialysis, the bed is immediately occupied by another in need of dialysis. In these instances, the participants had to turn away their patients or watch them suffer.

Zola expressed his emotions:

‘Your patient, sitting in front of you is in a wheelchair and is short of breath, has swollen legs and face and you can’t do anything. There is no space for him. You just get busy with a new patient in his bed.’

According to the participants, turning away of their patients without attending to their suffering, was seen as if the nursing profession had lost the altruistic values of being a nurse. This is in line with Watson (1985, p. 33) who stated that ‘the caring values of nurses and nursing have been submerged.’ In this context, Watson stressed that the increase in medical technology is one of the factors which impede the professional role of nursing and human care in the nuclear age. The nephrology nurses in this study, were unable to perform their roles as nurses as they could not alleviate the pain and suffering of their patients, when dialysis was withdrawn.

Compromised care provision to the patient

When dialysis was withdrawn, the participants expressed that they had no other way to continue with patient care as it was not only due to dialysis withdrawal but also the patients could not be admitted to other private health services. In this sub-theme, two theme-clusters were established as follows: (i) The Constitution of South Africa and The Patients’ Rights Charter and (ii) Nurses’ Scope of Practice and patient’s care.

The Constitution and Patient's Rights

The participants associated compromised provision of patient care with the Constitution of the Republic of South Africa (1996) which has set out the Patients' Rights Charter (2015) for healthcare but feel that these rights are violated. Firstly, the patients were denied admission to public dialysis units as their health status did not meet the public healthcare institutions dialysis admission criteria (South African National Department of Health, 2009). Secondly, the participants felt that their patients should have been offered the option of kidney transplantation if the patients finances were in a precarious position for long term dialysis and/or venous access failure. They further highlighted that the healthcare institution's finance department should have identified that dialysis would be a problem and therefore should motivate for transplantation – however this is not part of the financial administration responsibility. In addition, these nurses expressed their emotions that in cases of dialysis access failure, the medical staff should have adhered to the Patients' Rights Charter and motivated for transplantation.

These emotions were expressed by **Milani** and **Beauty**:

'According to the Constitution of South Africa, every person is entitled to quality healthcare. So, when I see the patient with kidney failure turned away because of the finances, I really see that as the patient's right to health is violated.' ... **Milani**

'My patient was young in his forties. His right to be cared for was violated. I feel that not every means was made available for his treatment.' ... **Beauty**

All these views indicated that the nursing profession and the healthcare system has lost the altruistic values about patient care. The nephrology nurses in this study also perceived the death of their patients as painful for them because the patients were denied their rights to basic nursing care. They witnessed suffering of their patients when brought into the units in life-threatening conditions to seek intervention and care. They mentioned that their patients

were escorted by their family members into the units in distress and were ordered by the medical personnel to refer them to the public healthcare institutions. The public healthcare institutions were also unable to provide any intervention and the patients were sent home to die. In some cases, the patients were brought back via the emergency/trauma units where they died. In these instances, the participants believed that the patients' rights had been violated i.e. a 'bad death.

This was captured in these two narratives:

'My patient's dialysis stopped due to financial issues. We couldn't dialysis him because of that problem. Doctor ordered us to send him to the state hospital, but we knew that even sending him there would make things worse as they did not have dialysis. He died there' ... Nicki

'I was on an early shift where there wasn't even the manager to speak to. It was a very bad experience. It was painful to see him suffering in my care. I contacted the doctor and he told me that the medical aid is suspended and ordered me to send the patient to the public hospital. In a few days later, I was informed that he died' ... Zola

A good death was described by the participants as an experience of being pain free, being with the family members and healthcare professionals during dying and death process. This was seen as the completion of life also described by Collins and Lehane (2013). This process is normally provided in palliative or hospice facilities. For Collins and Lehane, nephrology nurses explained that such moments could allow for the completion of life. In this process, the patient may be able to begin conflict resolution, spending time with family and friends and saying goodbye (Collins & Lehane, 2013). These authors further elucidated that this could be facilitated by early introduction of an advanced care plan. In doing this, patients and their families may be given the opportunity to discuss prognosis and become involved in decision-making about the best care when the patient's condition deteriorates (Collins & Lehane, 2013).

In my study, the nephrology nurses indicated that most of their patients who were withdrawn from dialysis, passed away in the hospital emergency units or in intensive care units (ICU). This was also a finding by Murray, Arko, Chen, Gilbertson, and Moss (2006) in the USA who reported that most of the patients withdrawn from dialysis died in hospital and in other institutions settings without hospice care. The authors also reported that 73% of these patients 'die with distressing pain, severe dyspnoea and other symptoms' (Murray et al., 2006, p. 148). The reasons of underutilizing hospice care by the patients with ESKD in the USA was associated with 'age, race, reason for withdrawal, ability to walk or transfer at dialysis initiation, and state of residence' (Murray et al., 2006, p. 1248). With regards to dialysis withdrawal, the causes were due mostly to failure to thrive and medical complications (Murray et al., 2006). The main cause of dialysis withdrawal identified by the participants in my study was the depletion of medical insurance funds. The participants highlighted this issue as a hindrance for their patients to access other private services and these patients had no other choice but to suffer alone as they were not eligible for dialysis in the public sector.

James referred to this in his following statement:

'When private dialysis is withdrawn due to no funds, it means that the patients cannot access other private medical care and have failed to meet the public healthcare criteria, so unfortunately the next call is death.'

The nephrology nurses in this study claimed that their patients had rights to palliative and hospice care just like other patients with terminal diseases, but they could not obtain access to these services. They believed that these services could help to control pain and support the family during the dying process. This finding supports many authors who raised a concern about the accessibility and underutilization of the palliative care services by the patients with ESKD (Davison et al., 2015; Germain et al., 2007; Gunda, Thomas, & Smith, 2005). These authors reported that the patients with ESKD at the end of life experienced similar symptom burdens, hence the need of the palliative care for this population of patients is important. For this reason, the participants viewed the care of their patients as the responsibility of the

government of South Africa, the custodian of the constitutional rights for all citizens. **Queen** stated:

'If my patient was given a chance to be transplanted, she could be still alive today. The government must allocate funds for patients with kidney disease. Admission criteria is a disadvantage and makes society to lose the important people who could still be reproductive for their families and the society as a whole.' ... **Queen**

In Sub-Saharan African countries, kidney transplantation and renal replacement therapy started in the 1960's, and South Africa (SA) was the first country to initiate this treatment option (Etheredge & Fabian, 2017). At that time, the apartheid system was in place and renal failure treatment was generally made available in the urban areas where most recipients were Whites (Fabian et al., 2016). In 1994, SA became a democratic country with a new Constitution whereby a new Bill of Rights was promulgated. In this Bill of Rights, all persons living in SA were given equal opportunities to healthcare; however, most of these rights can only be realized if there are adequate resources to offer service provision.

In relation to healthcare provision, the SA Constitution states that all people living in SA have the right to access healthcare services' (South African Government, 1996). In addition, these rights go hand-in-hand with other rights such as the 'right to life, the right to bodily and psychological integrity, and the right to freedom and security of the person' (South African Government, 1996). The nurses in this study, declared that their patients were denied all these rights. Their views support Etheredge and Fabian who criticized the rationing of policies as 'a human rights violation' which compromises the 'most vulnerable in the society' (Etheredge & Fabian, 2017, p. 11).

Nicki associated the care of her patients as a State (Government) obligation in her following narrative:

‘The State has the obligation to care for the people no matter what {with angry voice}. They can’t choose who to care for and who not to care for.’

In this regard, Section 27.2 of the Bill of Rights, justified the State’s measures of rationalizing healthcare services. This section reads that ‘the State must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights (South African Government, 1996). To respond to the issue of resource constraints and the high costs of dialysis, the State has set out an admission criteria for dialysis units in the form of a rationing policy (South African National Department of Health, 2009). Within this policy, the first condition for admission into the renal replacement therapy programme, is to meet the transplantability criteria as set out by the State (South African National Department of Health, 2009). The rationing policy also considers circumstances such as nationality, literacy, poverty, poor adherence to medical regimens and residential home conditions (Etheredge & Fabian, 2017; Moosa et al., 2016).

My findings are similar to the case of a patient named Mr Thiagraj Soobramoney in 1996. The patient was receiving dialysis in the private dialysis unit until his medical funds were depleted. He then sought the treatment from a public hospital but due to other medical conditions he was denied treatment. Mr Soobramoney approached the High Court of Durban regarding his right to access of healthcare services, but judgement ruled that he was denied because he was not eligible for kidney transplant due to his comorbidities (Southern African Legal Information Institute, 1997).

Etheredge and Fabian described the challenges of expanding access to dialysis in SA, and blamed the SA Government’s lack of prioritising for its citizen’s health (Etheredge & Fabian, 2017). In their report, it was evident that the countries at lower GDPs than SA (Table 5), have managed well their healthcare resources and provided dialysis to their population at a larger

number. This was further argued by Dhali (2012) who also condemned resource mismanagement by the stakeholders in the SA Government due to increased wasteful expenditure and corruption which affects the susceptible citizens. The nephrology nurses in this study strongly recommended that public healthcare services must meet the needs of lower income SA citizens regarding dialysis access and provision of palliative care. These nurses felt that the Constitution of SA had failed to provide care for patients with ESKD.

Queen described this in her following narrative:

'I just wish this country can have more dialysis facilities in the provincial side. Currently because of resources constraints, the provincial dialysis facilities are bound by the inclusion criteria which excludes many patients.'

Zola raised his concern about the post-dialysis facility in the following statement:

'There are no facilities for post-dialysis care like palliative care for the patients withdrawn from dialysis. All comes back to us and we are not trained regarding palliative care.'

Furthermore, these nurses mentioned that their patients' constitutional rights to healthcare provision was violated by the healthcare providers by adhering to the inclusion criteria. This issue was also raised by Etheredge and Fabian (2017) who reported that the selection guidelines set by the SA Constitution (2009) to select who is eligible for dialysis was not consistent in all regional provinces of SA. The authors raised a concern that the decision depended on the clinicians on site. It was for this reason that the Western Cape Health Department adopted a new guideline policy determining the selection process and decision-making as seen in Table 2 on page 4

Those who were declined as a result of age and comorbid disease formed the bulk of patients in the private sector. Access to dialysis for those candidates who have medical insurance (medical aid) is one of the Prescribed Minimum Benefits (Gunda et al., 2005) in the private sector which makes most of the patients who were rejected from public criteria to be eligible in the private sector as long as they can afford it (Etheredge & Fabian, 2017). The participants in my study sensed that their patients went to private dialysis facilities, just to prolong their lives in order to prepare for their demise.

Beauty expressed her frustration in the following statement:

'These patients have no other choice but to put the money together that they had saved go to the private hospitals to survive. Then they can say goodbye to their loved ones {crossing arms on the table}.'

Nicki stated:

'In the private dialysis, many patients are dependents on their relatives who can change their mind or also face financial difficulties, resulting in the medical aid being suspended for these patients. This is a just life-prolonging. So sad to see your patient suffering after dialysis withdrawal because of money issues. Better to not even start, if there will be no financial means to keep them going.'

The nephrology nurses frustration of using dialysis to prolong one's life was consistent with Grönlund and colleagues who reported that the nephrology nurses felt guilty when the purpose of dialysis was to prolong life but failed to meet this purpose (Grönlund et al., 2015). These nephrology nurses sensed that they were participating in their patients' suffering'. Most of the participants in my study believed that it was worthwhile that the patient and family's financial status was assessed before commencing dialysis especially in those who were elderly, had comorbid disease or who would not benefit from kidney transplantation. The participants in my study expressed concerns that irrespective of the patient's health

status and their comorbidities, the private sector hospitals were willing to admit them for dialysis. Further concerns for these nurses was that the patient's financial and/or medical aid assessment was not taken into consideration prior to admission. This situation often led to patient and family's finance and medical aid depletion which resulted in withdrawal of dialysis. This was expressed in the following participants' narratives:

'I think before admitting the patient in the private dialysis hospital, they should consider the family finances and advise not even to start.' ... **James**

'These criteria make it difficult to be admitted in government dialysis units, therefore many patients are filling the private dialysis units.' ... **Zola**

During the process of dialysis withdrawal, the participants encountered challenges in the delivery of good nursing care. Dialysis access failure and financial/medical aid depletion were the major challenges expressed by them. This they felt, was a contradiction to what is specified within the Constitution, relating to access to health care for all. The healthcare provider's policy for patients with ESKD and dialysis left these nurses apprehensive and somewhat saddened about their profession. This was viewed as a loss of the altruistic values in nursing and the general welfare of others. This is congruent with Watson's Human Caring Theory in which the first of ten carative factors is 'the formation of a humanistic-altruistic system of values' (Watson, 1988, p.5).

Nurses' Scope of Practice and patient care

The nephrology nurses were expected to practice according to the scope of practice laid out by the South African Nursing Council. In their practice, nephrology nurses as registered nurses are authorized to diagnose health needs and prescribe, provide and execute a nursing regimen to meet the need of a patient or group of patients or, where necessary, refer to a registered person (South African Nursing Council, 2004-2018b).

Within this context, the participants in this study were able to diagnose the patients' health needs and what would be the nursing regimen to provide care to their patients. However, they were unable to practice nursing care due to the policies of the healthcare provider. Furthermore, they could not refer their patients elsewhere due to SA Health Policies regarding patients with ESKD treated in the private hospital. This was emphasized by the Minister of Health in the constitutional guidelines for ESKD selection criteria, stating that 'patients who do not satisfy these criteria but who are nevertheless accepted on to a chronic renal dialysis programme in the private sector, should remain the responsibility of the private sector' (South African National Department of Health, 2009, p. 1).

Nicki expressed her stress regarding this issue:

When a patient is withdrawn from dialysis, you still have that patient's care within your scope of practice but in the private you have to abide to the policy and guidelines of the company which determine how far you can go within your scope of practice.'

The registered nurses are also expected to advocate for their patients so that they receive care and are provided with a safe environment (South African Nursing Council, 2004-2018b). The study participants tried to do the best for their patients to remain on the dialysis programme, but they failed. They contacted the patients' families and healthcare providers, treating physicians and medical aid companies with no success. When the patients were withdrawn because of dialysis access failure or because they had a poor prognosis, the nurses spoke to the physicians to rather care for their patients conservatively, but they were not heard and had to continue until their patients' death.

Queen related her story:

I tried to phone all over to get help, I really felt helpless that I could not refer my patient anywhere else for treatment until she passed on. Hearing that the man has left the house, I got him to pay a bit of the outstanding balance and she came back for dialysis, but after few

sessions he stopped again and ran away. It was embarrassing to tell the staff that she is not going to dialyze again after the fight I had.

And **Honey** related:

I am a nurse and I depend on the doctor's order and follow the company protocols...but keeping this patient on the machine without access was not helping her but was rather inflicting more pain and giving unnecessary traveling work to the family.'

Beauty pledged:

'You take the oath to help people but, in this case, you are bound to certain criteria of the company's policy and guidelines and rules, you can't practice it, you really feel disappointed' {scratching her head}.'

Zola stated:

'As nurses, we pledge to care for the patient, but the company policy and procedures make the care chaos, because they interfere with this pledge. The nephrology nurses care for the patient, the family and the company.'

The participants expressed that their scope of practice to care for their patients was compromised by these policies.

Queen explained:

You really have to be honest. I couldn't put my patient on the machine even though there was an empty bed, that will be stealing from the company. You must be loyal to your company.'

The participating nurses in this study viewed the compromised provision of care for their patients withdrawn from dialysis as a “loss of nursing altruistic values.” Their opinions are in line with Watson who viewed the nursing profession as founded on the formation of the Humanistic-Altruistic System of Values’, among her ten carative factors (Alligood, 2018, p. 68). Watson highlighted that this system is based on ‘practicing of loving kindness and equanimity within the context of caring consciousness towards self and others’ (Alligood, 2018, p. 69).

Opting to act accordingly to their own conscience and the expected scope of practice, they were almost forced to follow the healthcare provider’s policy which placed them in an awkward position. The participant nurses felt unsafe to act against their own consciousness about patientcare when they had to watch or turn away their suffering patients without practicing what is required from them as stipulated in their scope of practice.

This was captured in the agitated reaction from the participant **Nicki** when I asked about the question of how caring for the dying patient after dialysis withdrawal, affected her own interactions with others.

‘Watching a patient struggling to breathe in your face and doing nothing to relieve that suffering, it can be seen as a professional negligence. From the previous event of my patient who died in the unit, I learnt a lesson of not allowing the patient who seems to be unwell in the unit. I refer them to trauma or send them back home if no medical aid. I usually talk inside me “don’t die here, just wait and go die at home” {hitting the table with knuckles}.’

Here the participant refers to the rules setting out the acts or omissions in respect of which the Council may take disciplinary steps (South African Nursing Council, 2004-2018c). These include the following:

‘Wilful or negligent omission to carry out such acts in respect of the diagnosing, treatment, care, prescribing, collaborating, referral, coordinating and patient advocacy as the scope of his profession permits’.

‘Wilful or negligent omission to maintain the health status of a patient under his care or charge, and to protect the name, person and possessions of such a patient.’

The participants also feared for their safety from angry family members. In addition, they feared losing their jobs and had to follow the policy of their company as set out in their working contract. Consequently, some of them were preparing to resign and others developed an avoidance complex as a coping mechanism.

These sentiments were captured in the following participants' statements:

We as nephrology nurses, working in the private dialysis unit, we follow the nursing scope of practice but also the company guidelines which sometimes conflict one another. You have no choice but to follow your employer's orders. You have signed an employee's agreement and job description, you have to maintain that integrity, to be a good representative of the company.' ... **Beauty**

'Like I said it took me sometimes to recover from that emotion, but I am still experiencing same problem. The patients are being refused dialysis because of this medical aid thing. No, no, no, I am thinking of leaving this nursing profession.' ... **Zola**

'I stopped talking with her husband and the patient as I also moved to the managerial position, I got busy. I was lucky I moved from that unit. After her death, I thought this man will come back to the unit to look for me because I was angry with him and it was like harassing him to pay for his wife's dialysis.' ... **Queen.**

5.1.4 Main Theme 4. *being-with-death*

The theme of '*being with death*' emerged from the phenomenological conversations with the participants. Their concern was that their patients' life depended on dialysis and when this treatment was withdrawn, death followed in a few days or weeks. Being aware that death was taking their patients away, they regarded them as dead. This made the '*being with patients*' in a caring relationship as discussed above (Parse, 1988) , to become '*being with death*' (their dying patients). I have used the phenomenological way of italics and hyphens to demonstrate how Heidegger refers to death from a philosophical context. I also find that it fits in with the phenomenological approach that I chose for this study.

When I was collapsing my sub-themes, I took my supervisor's advice to read excerpts from Koestenbaum's (1976) book on '*Is There an Answer to Death?*' In his writings he searches for positive meanings of our personal ontological confrontation with death. I found that using Koestenbaum's thinking, I used his two of ten points of view to assist in refining this main theme.

1. By recognising death, the individual is on the way to becoming decisive and
2. By remembering the death, the individual concentrates on essentials.

The following sub-themes informed the main theme of *being-with-death*, including (i) watching and waiting and (ii) re-living the event of death.

Watching and waiting

Watching and waiting sub-theme was identified from the theme of *being with death* for the following reasons: The nephrology nurses in this study, mentioned that when dialysis was withdrawn due to the funds, the patients and their families were notified not to come to the unit until the issue was resolved, but they were still coming. This could be because the patients and their families had developed a dialysis routine and also would try their luck. Other reasons for the patients to come to the units despite their withdrawal, was their intention to protect their families against their dying burdens and rather speak to their nurses with whom they had developed a bond with.

This agrees with the study of Brokalaki and colleagues who reported that the patients with ESKD seek to spare their families the additional illness burden and rather share their challenges with their nurses (Brokalaki et al., 2001). The authors stressed that these nurses were profoundly affected, resulting in a high level of anxiety and depression. Another reason mentioned by the participants for which their patients withdrew from dialysis, was the moment they got into crisis and their family did not know what to do. In this case, the family

members rushed their patients into the units as most of them were withdrawn due to the lack of funds, which meant that they could not be admitted into the private emergency centres.

Watching their patients in that life-threatening condition while they could not relieve that suffering was overwhelming to these nurses. For the participants in this study, it appeared that their presence and exposure to dying and death(s) of their patients was more pronounced than in other disciplines of acute care nursing such as intensive care, cardiology and trauma. I interpreted their experience this way because in these facilities, the patients are in a critical condition and busy dying, but at least the nurses are doing something and are not on the frontline, meaning they are not left alone. In addition, they are not turning their patients away without treatment, as is the case for these nephrology nurses who just watch and wait for the dying process of their patients. In this sub-theme of '*watching and waiting*', two theme clusters were identified namely (i) severing of the life-line and (ii) emotional support needs.

Severing of the life-line

This theme-cluster was analysed from the participants' narratives in which they related dialysis as a life-line. This simply meant that when a patient is diagnosed with ESKD, the only way of surviving is a dialysis machine. The nephrology nurses in this study, explained that when dialysis is withdrawn, it means that this life-line is severed and will result in patient's dying and their eventual death. This study finding is similar to the study carried out in Sweden by the renal nurses, Hagren, Pettersen, Severinsson, Lützén, and Clyne (2001). In their qualitative study, 19 patients with ESKD on dialysis, described dialysis machine as their life-line as it kept them alive. The participants in their study stated that without dialysis they would die. In the current study, when dialysis was withdrawn, the participant nurses had nothing else to do but to wait for the death to come and take their patients.

Beauty related to this:

'Patients with ESKD withdrawn from dialysis can die anytime, it is just a matter of time {thighs deeply}.'

Being aware that after dialysis is withdrawn, death follows; the participants in my study began to start worrying. In this context, the overall participants described death as a thief who comes to steal and take away their patients into another world.

Death is like a thief stealing my people. When a patient dies, I reflect on their previous death experiences. Death lives in us, when I see patients suffering, I just pray for them to die peacefully.' ... **Milani**

'When the dialysis was withdrawn, I knew that I was losing a friend. I started to prepare myself, to sort of telling myself that I have done my best and now this is the time to distance myself, because tomorrow I may not find you here, that you are gone to the afterlife world.' ... **Jane**

Dialysis as a life-line for the patients with ESKD, was also described as a dependency relationship between the nurses and the patients and also as a protection for the patients against the death (Hagren et al., 2001) . In this study, the nephrology nurses, being unable to provide that protection, opened the way for the death to come in and take their patients.

Beauty expressed her defeat:

My hands were tight, my heart wanted to carry on (connect him to the machine), my outside couldn't because I am dependent on the company policy.'

And **Nicki** added

'My hands are tight. If I had money, I would not let him die, I would pay for his dialysis sessions.'

The participants' lack of protection for their patients against death, also made them realize that their patients suffering could only be relieved by death. In this instance, they allowed the death to come and take their patients to the place of rest and peace.

These sentiments were found in the following participants' narratives:

Knowing that there was no other means of treatment I knew the end was death and I just saw a better life in the after-death space, there will be no need of dialysis.' ... ' Nicki

My patient suffered a lot, I have done what I could, and I put other into God's hands. Caring for the dying patients is part of my job, so I care for them when alive and when dying. May his soul rest in peace.' ... Jane

Emotional support needs

The 'emotional support needs' was identified as another matter needing attention in this study in the sub-theme of '*watching and waiting*.' The nephrology nurses raised this issue as they had inward fight after their advocacy for their patients has failed. They were left alone with their suffering patients, which increased their anxiety and stress levels and raised their desires to see government intervention in increasing the dialysis facilities and allowing the patients withdrawn from dialysis admission to be admitted into palliative and hospice care. Their reactions are validated by their lack of palliative care training in the nephrology nursing. This finding is in keeping with Zyga et al. (2011) study, where nephrology nurses reported the need of palliative care to enable them to care for their patients at all levels. The participants in the current study narrated this experience in a similar manner to the previous study. This was illustrated in the following narrative:

'There are no facilities for post-dialysis care like palliative care for the patients withdrawn from dialysis. All came back to us, while we are not trained regarding palliative care' ... James

They also felt the need for support after their patients 'death, as they were dealing with the grief experience. Their grief was not recognized; they were not given an opportunity to mourn for them. This caused them to experience disenfranchised grief as explained in Doka (2002). Doka stressed that 'disenfranchised grief is experienced when a loss cannot be openly acknowledged, socially sanctioned, or publicly mourned' (Doka, 2002, p. 161). In this case, the participants, felt that there is no policy from their company or stipulated rule in SANC Scope of Practice regarding grieving after their patients 'death, hence no legitimate right to grieve after the death of their patients with whom they developed a bond.

Beauty shared her experience as follows:

'After your patient's death, you have to grieve on your own way and carry on with the work.'

The emotional support for the nurses caring for the patients with long-term illness is important to prevent deprived grief consequences as described by (Leick & Davidsen-Nielsen, 1991). The authors highlighted that the avoided grief may result in psychosomatic and psychological symptoms including physical pain with no apparent causes, peptic ulcers, heart disease, asthma, headaches and other ailments (Leick & Davidsen-Nielsen, 1991). This was supported by the findings in the study carried out by Rickerson et al. (2005), exploring the prevalence of grief related symptoms and the need for bereavement support for nursing staff. These authors reported that the nursing staff who experienced more symptoms were those who encountered more deaths, worked a long time in the field and had developed a bond with the patients who died. In my study, the participants reported similar symptoms especially the sleeping disturbances, unexplainable body pain, fatigue and difficulty concentrating.

For example, **Milani** said:

‘When my patient passed away, I was not sick, but all my body was sore, and I could not explain my feelings, I was just numb.’

Another significant issue which was revealed from the narratives of the nephrology nurses in this study is the fear to face the family members of those patients in their care who passed away. The participants verbalized being worried about their safety, after their patients’ death especially outside the hospital environment. This factor of fear by nephrology nurses was not found anywhere in literature.

Milani illustrated this in the following quote:

‘That’s why I didn’t want to go to visit him. His family is also from my side. To them it is like, it is me who didn’t care properly for this patient.’

Re-living the death event

The ‘*re-living the death event*’ sub-theme was identified as a real experience for the nephrology nurses in this study. The main reasons of this experience were that their patients when withdrawn from dialysis, were sent home and died either at home or in the emergency unit. Some of the participants said that they were not allowed to go to visit them at home, and others were unwilling to reconnect with the patient’s families’ due to them feeling shame and guilt and fear of being hurt. For this reason, they did not have a chance to say goodbye to their patients and to end their relationship with them. In this concept, the aspects of (i) unfinished business and (ii) ontological confrontation were found to be important to explore further.

Unfinished business

The participants have an established relationship with their patients which is congruent with Parse (1988) definition of caring. The author explained caring as: '(i) risking; (ii) being with someone towards a moment of joy' (Parse, 1988, p.130). The nephrology nurses took the responsibility to care for their patients and promised to be with them in this caring continuum. When dialysis was withdrawn, the patients were sent home and died without their nurses by their side. For this reason, these nurses sensed that they had not completed this caring promise and have not finalized the end of that relationship. They mentioned that since dialysis was withdrawn, and the impending death was obvious, it could be beneficial for both the nurses and their patients to share that dying moment. Sharing their (nurses and patient) lived caring relationship could allow them a mutual consolation, hence providing them with a peace of mind.

In the study carried out by Tornøe, Danbolt, Kvigne, and Sørli (2015), it was reported that the dying patient could be consoled in the nurses' presence and the nurses could observe that their dying patients moved from the state of suffering distress to a state of peace and hope. In this regard, the nurses felt they had finished their caring business with their patients. In contrast to my study, the participants emphasized that when their patients died, this relationship was interrupted by dialysis withdrawal process and they were not next to their beds, they were only informed by their patients' relatives of their patients' death.

Nicki gave an account of her experience as follows:

'When the patient is withdrawn from dialysis, when they die you are not next to the bed; you hear the family informing you that they are dead.'

Another reason of failing to have a relationship closure with their dead patients was their inability to attend to the normal after-death rituals such as a funeral or memorial service. This could also allow them an opportunity to say goodbye to their patients and provide them with a sense of closure. During the phenomenological conversations, the main reasons for not attending to the rituals and the funeral services were due to work, and other reasons were related to their safety, shame and guilt in having to face their dead patients' relatives. This is another new insight as no current literature supports this.

Zola shared his experience:

'Even though I could not speak to the patient or family, I kept following up his condition by an outsider (a colleague patient). I kept thinking about him because I did not want to face him or his family again. In this instance, you fear to face the patient and family as you failed to save their family member.'

The emotions of re-living the loss of their patients were evoked during anniversaries or on holidays, or when encountering another death. The participants had recurring images of their dead patients when some common event with them appeared; such as a song, watching a TV program together, a religious act or just a joke.

'That week I lost my patient at the same time my dad was dying. The Monday the patient died and the Wednesday my dad died. I was still emotional of the death of my patient when I lost my dad.' ... **Nicki**

'I used to watch cricket with him, and even today when I am at work and cricket is on TV, I remember him and realize that he is not here anymore.' ... **Jane**

These situations appeared as a form of unprocessed grief and unfinished business of letting go and saying goodbye. In this study, the participants are still living with their dead patients and have not handed them over to their final resting place to be subsequently freed from the obligation of mourning as explained in Hertz (2013). The author clarified that to have that

final closure with your dead person, it is a mandatory that you follow them to the final resting place and ensure they have been well welcomed by the souls who are buried there (Hertz, 2013).

Ontological confrontation

The Encyclopaedia of Death and Dying (2018), described the concept of ontological confrontation as follows:

‘Human beings have a degree of awareness of personal existence not found among other species. This awareness, the province of ordinary people as much as philosophers and theologians, encompasses the finitude of life, the personal existence of others, the possibility of other worlds, and the questions of when people came into the world, why they are on earth, and what happens when they die.’

Nugent (2013) defined ‘ontological confrontation as the precise and immediate knowledge of individual mortality which can arise whenever a person's regular defences toward death awareness are intruded upon by situations or surfacing memories’. In my study, the situation of being exposed to the dying process of their patients made them alert of their own death. All of the participant nurses displayed awareness that they will die but emphasized that they did not want to die from ESKD.

‘I know I will die but I pray not with a kidney failure. Is not good. It is painful disease.’ ... Nicki

The participant nephrology nurses displayed death anxiety especially if they should develop ESKD. This was due to their experiences of constant exposure to their patients’ suffering. For this reason, many of them were taking precautions to prevent this disease.

'Yes, I fear dying with kidney disease that's why I now drink a lot of water to prevent this disease, I don't want to die with kidney failure {Shaking head}.' ... **Beauty**

'I even think of myself when I am paying medical aid, I think of how I will be treated if I get sick with this disease.' ... **James**

In line with this finding, Koestenbaum (1977, p. 11) among the ten consequences of death anticipation, he has stated that by the fact that 'man cannot escape death', he must accept that 'he has been condemned to death', thereby 'start living' and be able to 'neutralise the fear'. The author further believed that by 'accepting death, the individual is inspired to 'take charge of his own life' (Koestenbaum, 1977, p. 11).

Even though there was an indication that the participants accepted death as part of life, they still feared the unknown life after death. This anxiety was evoked by the fact that they had no clue of what happens in the after-death space which many of them referred to as another side. During the phenomenological conversation, they divulged that no one wanted to die, but as death is inevitable, they would rather die from old age.

'Of course, I fear death because I don't know what happens in the after death {Opening her eyes wide, staring on me}.' ... **Jane**

'Everyone will die, but I would like to die peacefully. Not now though, when I am old. I just sleep and die in my bed {Smiles}.' ... **Queen**

The nurses' death anxiety is in keeping with Koestenbaum (1977) who highlighted that the unconscious cannot perceive death and has no knowledge about it. The author explained that human beings have no knowledge of death as they tend to detach their conscious to it (Koestenbaum, 1976). He explains further that 'every object has attached to it a stream of consciousness connecting with some ego, therefore unless the object connects to some ego,

we cannot meaningfully ascertain even that the object exists' (Koestenbaum, 1977, p. 108). This highlights the fear of unknown that these nurses face about death as they would rather opt to not thinking about it. In this context, it was evident that the participants would not want to conceptualize their own death and this fear made them to resist death. The fear of facing the reality of death was observed during the conversations by all of the participants. When referring to the death, they used words such as "*my patient passed on or passed away*" instead of '*died*.'

'He got very sick and the family took him to the state hospital and he passed away there'...
Nicki

'Seeing that there was nothing else could be done, I started giving up in mind but not in actions. I continued caring for the patient until the end of life. Patient was sent to trauma unit and passed on {With a sad voice}.' ... **Honey**

Another concern that was highlighted by the participants in facing their own death was related to their families and their dependents. Seven of the participants in this study were parents with young children and one was living with their grandchildren. Since no one has come back from the 'after-death space', all of the participants sensed they would leave their children miserable if they would die as they would not have a chance to return and raise them up.

'I don't want to die now. I am still too young, and my children still need me. I have no choice that I will die but only when I am old, and my children are grown up, then I can die' {Closes eyes, pauses}. ... **James**

Ellis, Wahab, and Ratnasingan (2013) suggested that the reason the fear of one's death is apparent is that the dying event mostly happens with significant pain and brings closure to the pleasures of life, including family relationships. In my study, the nurses were mostly worried about their children and this was seen as an area for further investigation as the literature I reviewed did not offer any explanation of how being a professional nurse and a

parent influences the anxiety which follows death. After my literature review on this topic, I reflected on it and I wrote up a journal entry:

Journal Entry, 18 April 2018

This topic is so worrisome. The patients with ESKD suffer in many ways and their suffering affects nurses. Literature consulted offers more about patients with ESKD palliative care plan, but few have accessed these facilities before death. This became the responsibility of the nurses who were already overloaded with other patients. These nurses experience the suffering not only at work but also outside the work environment. No literature was found about the experience of these nurses caring for these patients after dialysis withdrawal. The nurses got involved with their patients' lives, build relationships with them as this is the culture of nursing profession to be able to care for the patient.

However, in this nursing specialty, this relationship often does not end well, hence leaving nurses frustrated and fearful for their own safety. The suffering experienced by these nurses ranged from being hurt to the fear of their own death. Being powerless in decision making put them in the situation where they became nothing. They stood in front of their patients, suffering but were unable to intervene and relieve that suffering. They rather detached from their patients and their families who became significant others. When their patients died, they associated themselves to the causes of their deaths as they turned them away while in the life-threatening situation. The witnessing of their patients' suffering brought on a fear of their own deaths. This appeared to be so frightening even to myself. During this study, I just learned that death is the final stage of growth which put me in the situation of seeing death as an invisible but a friendly companion on my life's journey. I believe this increased the knowledge of my identity of who I am and also taught me to live my life more fully.

The managerial, educational and detachment aspects were the most concepts that constantly came into my mind. These aspects would mean a lot to apply changes to improve the service these nurses are giving to the patients in their care as well as to themselves.

All the participants agreed that they needed education regarding caring for the patients with ESKD withdrawn from dialysis. They also expressed the need of death and dying education and support after their patients' death. The participants indicated that there was no guidance regarding caring for the patients after dialysis withdrawal, as there was no guideline or policy of how to perform this care. These nurses also demonstrated a need for debriefing and counselling skills to manage their death anxiety. They also showed that their detachment with their patients after death needed an emotional support but claimed that their managerial support was inadequate.

Tranter et al. (2016) also identified inadequate support systems in place to care for dialysis nurses when their patients die. The authors commented that due to the relationship with their patients, they needed bereavement support after their patients' deaths. Their study recommendation was the introduction of an education program regarding healthy ways to cope with deaths of their patients. To lighten their fear of death, they further recommended the ongoing dialysis withdrawal education and its subsequent condition deterioration and death. Furthermore, the communication skills with the patients and their families after dialysis withdrawal should strengthen their ability to cope (Tranter et al., 2016)

5.2. Conclusion

The aims of this study were:

1. To explore and describe nephrology nurses' experiences and emotions when caring for dying patients and uncovering coping mechanisms to deal with deaths of patients with ESKD

2. To identify nephrology nurses' knowledge gap in caring for the dying and preparing for the deaths of patients following withdrawal of dialysis
3. To determine the emotional and educational needs of these nephrology nurses and offer teaching and learning recommendations for this group of nurses.

Their lived experiences were explored through their narratives and observations and found that caring for the patients with ESKD withdrawn from dialysis was emotionally demanding for these nurses. Emotional trauma was the major finding and a significant challenge to address in this study. Irrespective of their feelings after dialysis withdrawal, the nephrology nurses continued to advocate for their patients until they exhausted all means. That was seen as their continuous commitment to provide professional and quality care to their patients and their families.

Nephrology nurses experienced negative emotions which resulted in suffering when they failed to advocate for their patients dying after dialysis withdrawal. These nurses continue to be in contact with their patients and witness their suffering without intervening to alleviate it. The experience of powerlessness made them to feel hopeless and they started to envision the deaths of their patients and at time themselves. Therefore, they started to detach themselves from their patients, their families and the nursing profession. This was used as defence mechanism for them to be able to continue to care for other patients.

The nephrology nurses felt that they themselves were acting against their professional role of a caregiver, by turning away their patients thus leading to the conclusion that the nursing profession had lost its altruistic values.

The ontological confrontation was also revealed by the nephrology nurses when facing the reality of their inevitable death. The lived experiences of the participants in this study has offered some answers from a South African perspective regarding nephrology nurses' lived experiences of caring for patients with ESKD dying following dialysis withdrawal.

The knowledge gap in caring for the dying and preparing for the deaths of patients following withdrawal of dialysis identified concerns the policy makers. The nephrology nurses in this study have expressed their concerns regarding this care as there is no policy or guidelines to follow after dialysis withdrawal.

Lastly the emotional and educational needs were acknowledged including death and dying education, support one other, debriefing and counselling skills to manage their own death anxiety.

5.2.1. Recommendations for Further Research

The following proposed recommendations are based on my study findings and concern the educational needs, clinical practice, nursing management and research.

Nursing Education

Most of the patients with ESKD treated in the private dialysis units are elderly and others present with many comorbidities, making them ineligible for kidney transplantation and therefore end of life or hospice care. As with most specialisations in nursing, education around end of life care is imperative. This education intervention may help nurses to deal with their patient dying process after dialysis is withdrawn and also to deal with their own death anxiety.

Ongoing education regarding the grief process and healthy coping mechanisms after the death of their patients was also found to be essential to help them deal with related emotional trauma experiences. This includes debriefing skills which may improve their interaction with the colleagues. This debriefing may reveal the most affected staff, thus identifying earlier in providing emotional support.

Clinical Practice

The nephrology nurses develop a bond with their patients and their families' due to the constant dialysis sessions' times with them. This could give them the opportunity to introduce the advanced directives and the advanced care plan (ACP), to their patients and their families. In doing so, this may encourage open and ongoing conversations between patients, their families and the healthcare providers regarding all aspects of death and dying.

Nursing Management

Nurse managers may need to consider providing support for nephrology nurses while caring for those patients who die and after the death. This can be done through formal and informal systems and may be of a great benefit to the nursing interpersonal relationship and the nephrology nurses' working atmosphere.

Having regular formal and informal debriefing meetings with the nephrology nursing team may prove useful to assist them to reflect upon their experiences of caring for their dead patients.

A standard policy and procedure regarding the caring for the patients withdrawn from dialysis should be provided. This may prevent nurses' fear of being hurt by the family members of their patients and the fear of losing their jobs due to not caring for their patients while suffering, as stated by their governing body (SANC) in the scope of practice.

A guideline to mourning and grieving for all healthcare personnel may be considered beneficial. A unit initiative of a memorial wall may be a way of sharing the nurses experiences and bonds of patients who have died from ESKD

The concept of mourning and grieving for nurses after the death of their patients who have become significant others to them, appears to have been omitted and this may be another area of research in the future.

Further research is also needed in understanding the experiences of nurses caring for dying patients after life support has been withdrawn in other nursing specialties.

5.2.2. Strengths and Limitations of the Study

Reflecting on my personal journey, gave me confidence that I have learned equal amounts about care of the patient with ESKD after dialysis withdrawal and the research process. In the research process, I believe I have achieved my personal objectives, but this does not mean that I have achieved this study's aim in all its aspects. The strength of this research was my participation in teaching and learning with the participant nephrology nurses in the research setting which provided a mutual trust for both myself and them. The rapport and relationship of trust allowed for me a sense confidence for both me and the participants to engage in dialogue, hence a good quality of phenomenological conversations and information gathering.

The participant nephrology nurses' experiences were specifically and personally accounted for and it may be difficult to apply the results of my study to other groups of nephrology nurses caring for the dying patients with ESKD after dialysis withdrawal. Another limitation may be that this study was conducted in two private dialysis units and therefore the findings may not be the same if conducted in a public hospital. However, other nephrology nurses may see a similarity with the descriptions of the experiences of caring for these patients.

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Appendix A: PARTICIPANT INFORMATION SHEET

Dear participant

You are invited to participate in the study exploring Nephrology Nurses' lived experiences of caring for dying patients with End Stage Kidney Disease (ESKD) following withdrawal of dialysis.

The objective of the study

Terminal care for this group of patients with ESKD is different in many ways in that the time-frame from dialysis withdrawal to death is often short. Withdrawal from dialysis is most frequently due to financial and resource constraints, dialysis access failure (arteriovenous fistula, hemodialysis or peritoneal catheters) and comorbidity.

Caring for dying patients with ESKD after dialysis withdrawal may cause nephrology nurses to experience prominent level of death anxiety, guilt, inadequacy and even helplessness. This may be due to long and deep bonds that have formed over many years.

It is hoped that the nurses' experiences will offer recommendations for their own emotional well-being and educational requirements to better prepare themselves to cope and grieve.

The phenomenological conversation

The researcher plans to conduct the phenomenological conversations with the participant in a suitable venue in the study setting ensuring privacy and non-interruption of the phenomenological conversation, lasting approximately 45 to 60 minutes (It might be longer). This will be done according to your indicated convenient time.

Please note that phenomenological conversation is a form of semi-interview in which the researcher and the participant are both engaged in dialogue about a phenomenon. In this study, we will be sharing the Nephrology Nurses' lived experiences of caring for dying patients with End Stage Kidney Disease (ESKD) following withdrawal of dialysis.

Once the first phenomenological conversation's transcription is completed, a feedback session appointment will be set up. A second phenomenological conversation may be required to authenticate the unravelled information from the initial phenomenological conversation.

Confidentiality of responses

To adhere to the confidentiality principle during the study, you will choose your own pseudonym which will be assigned for your conversations. Your anonymity will be protected at all times. Only the researcher will know both your name and your chosen pseudonym. The phenomenological conversations will be recorded on audiotape. You will be required to sign consent form prior to the conversations and feedback sessions to guarantee the audio-record permission, and in addition to use the information you have provided when the study is being written up.

All original information from the phenomenological conversations will be kept in a secure locked cabinet. When the transcriptions are finalised, any electronic recordings taken during the information gathering will be encoded and stored on a CD or USB Flash Drive. Those original digital recordings will be deleted. No raw information with your identifying information will be accessible to any person other than the research team of this study. However, given the nature of the study, the highly

specialised topic and the small sample size, despite all measures taken to protect the confidentiality, it is possible that participants may be identifiable in any ensuing dissemination of the study findings as for example direct quotes used in publications.

Benefits to individual participants and potential societal benefits

You will not directly benefit from participating in this study, however your participation will contribute to knowledge of the experiences of nephrology nurses caring for dying patients with ESKD after dialysis withdrawal with whom they had an existing bond. You will also gain knowledge about how to cope and grieve after the deaths of patients with ESKD. The study's results may provide the nurse managers a better understanding of the challenges faced by the nephrology nurses caring for dying patients with ESKD and in doing so, finding a way of overcoming those challenges. There will be no remuneration in participating in the study, but refreshments will be made available during the phenomenological conversation

Risks associated with the research study

The researcher acknowledges that this is a very sensitive research area since it will be exploring the aspects of care that may be uncomfortable or distressing. In this case if you experience any distress or discomfort during the phenomenological conversation, the session will be suspended, and a debriefing session will be provided immediately by the researcher and if necessary, provides referral resources for further psychological support. The researcher will make sure that you are safe throughout the study. In addition, given the nature of the research topic, it is possible that this study might highlight the resource allocation issues around nephrology dialysis and the associated ethical concerns. It is possible that you may not feel comfortable to talk about resource allocation issues because of potential consequences for current or future employment as a nephrology nurse. The researcher will assure your confidentiality and you are not compelled to share things that you are not comfortable to do so.

Right to withdraw

Please be advised that there is no obligation to participate in this research, your participation is voluntary. You can withdraw at any time even in the middle of your questionnaire, without any

consequence or penalty. Once you have withdrawn from the study all information that you have provided will be omitted from the study and destroyed.

Dissemination of the findings

Once the study is completed, the researcher will present the study findings in the form of the research report and this will be submitted to the University of Cape Town for examination as a Masters' thesis. The research report will be made available to your institution and at the Human Resources (HR) of the dialysis provider company. The researcher also plans to have an oral presentation of the findings in a conference when offered an opportunity. The results will be published in both local and international journals

The permission to conduct this study has been approved by the Faculty of Health Sciences Research Ethics Committee (HREC №) University of Cape Town and the HR from the selected dialysis units.

Contact details

If there are any queries about the study or to participate in the study, please contact me (DB Bidii), on my cell Number 0725817643 or send me an email at bdxdem001@uct.ac.za.

Participants can also contact my supervisor Dr N Fouché, at 0214066672 or email nicki.fouche@uct.ac.za.

If you have any concern about the ethical conduct of this study, please contact the UCT-FHS Human Research Ethics Committee, the University of Cape Town on +27214066338. Or write to Shuretta Thomas, Human Research Committee, Room E52-24, Old Main Building, Groote Schuur Hospital, Observatory 7925, Cape Town, South Africa

Thank you



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Appendix B: CONSENT FOR PHENOMENOLOGICAL CONVERSATIONS AND FEEDBACK SESSIONS

Agreement and signatures

I, (research participant) have read and understood the information sheet and do hereby give consent to participate in this study. I have been explained and understood the nature, the purpose and method of this study and agree to participate as long as my confidentiality will be observed as outlined above. In this consent, I agree that the conversation transcripts with my identity concealed, can be used for the purposes of this study and thereby guarantee the permission to **audio-record the conversation**.

Signed:

Preferred Participant Pseudonym:

Date:.....

I, DB Bidii (researcher) undertake that the right to confidentiality of the participants and all information obtained as a result of conversations with them will be highly respected.

Signed:

Date:



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Appendix C: THE PHENOMENOLOGICAL CONVERSATION GUIDE

The initial phenomenological conversation

Tell me, in your own words, your personal experience regarding caring for the dying patients with ESKD after withdrawal of dialysis.

The phenomenological conversation prompts:

1. Are there any specific incidents or situations that stand out for you?
2. How would you describe your relationship with this patient?
3. Or with his/her family?
4. What does death mean to you?
5. What was it like caring for patient(s) after dialysis withdrawal?
6. Have you ever been trained about how patients with ESKD may die after dialysis withdrawal?
7. What training would you like to receive regarding this care?
8. Do you receive adequate support after a patient's death?
9. Please describe how this care has affected your self - interactions and relations with others
10. What do you not like about caring for the dying patients with ESKD after dialysis withdrawal?

Appendix D: PERMISSION TO CONDUCT A RESEARCH FROM NATIONAL RENAL CARE.



21 August 2017

Boniface Bidii

RE: PERMISSION TO CONDUCT RESEARCH IN THE WORKPLACE

This letter serves to confirm that the management of National Renal Care has granted you permission to conduct research (provided that the research policy has been signed and are complied with) in the workplace and to have controlled access to NRC's resources and patients in terms of the research policy.

Please read and initial each page of the attached policy and sign last page on space provided and return to Human Resources Department.

Conditional approval subject to ethics approval.

Should provisions of the research policy not be complied with, this privilege may be withdrawn.

Yours sincerely,

signature removed to avoid exposure online

HR DIRECTOR

26 Cedar Avenue Richmond 2092 • Private Bag X8 Briton 2019 • Telephone: (+27) 011-726-5206 • Fax: (+27) 011-726-8641
Directors: EL Jacobs • E Keyser • FP Ntloke • MY Mangel • N Phillipson • RR Souter • CL Sheen • CD van der Bergh

www.nrc.co.za

Appendix E: FACULTY OF HEALTH SCIENCE HUMAN RESEARCH ETHICS COMMITTEE



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: sumayah.ariel@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

31 July 2017

HREC REF: 401/2017

Ms N Fouche
Department of Nursing
Health & Rehab
F-45 OMB

Dear Ms Fouche

PROJECT TITLE: AN EXPLORATION IN TO NEPHROLOGY NURSES' LIVED EXPERIENCES OF CARING FOR DYING PATIENTS WITH END STAGE KIDNEY DISEASE FOLLOWING WITHDRAWAL OF DIALYSIS (Master's candidate-D Bidil)

Thank you for your response letter dated 17 July 2017, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 August 2018.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: - D Bidil will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

Yours sincerely

Signature removed to avoid exposure online

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 401/2017

HUMAN RESEARCH ETHICS COMMITTEE

20 JUL 2018

UNIVERSITY OF CAPE TOWN
FACULTY OF HEALTH SCIENCES

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

This serves as notification of annual approval, including any documentation described below.	
<input checked="" type="checkbox"/> Approved	Annual progress report of annual
app	proved
<input type="checkbox"/> Not approved	See attached comments signature removed
Signature Chairperson of the HREC	
Date Signed 23/7/18	

until next renewal date 30 07 20

Comments to PI from the HREC

Principal Investigator to complete the following:

Date (when submitting this form)	2/07/2018
HREC REF Number	401/2017
Current Ethics Approval was granted until	31/03/2018
Protocol title	AN EXPLORATION INTO NEPHROLOGY NURSES' LIVED EXPERIENCES OF CARING FOR DYING PATIENTS WITH END STAGE KIDNEY DISEASES FOLLOWING WITHDRAWAL OF DIALYSIS.
(if applicable) Protocol number	N/A
Are there any sub-studies linked to this study?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each s	
Principal investigator	Dr Nicola Fouché